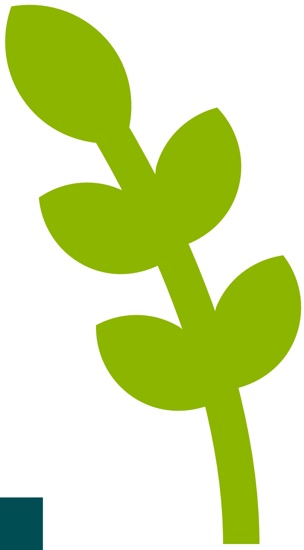
Strategizing Transdisciplinary Research Priorities around the impact of COVID-19 control measures on people with dementia and care partners living at home:

A 14 COUNTRY PERSPECTIVE

THE STRAP CONSORTIUM



CONTENT

1. EXECUTIVE SUMMARY

People with dementia and their care partners, particularly those living at home, were disproportionally affected by the COVID-19 pandemic. These individuals experienced significant negative impacts of COVID-19 control measures, such as social isolation and closure of services.

During the peak of the pandemic, national and local governments were forced to make quick decisions in a context of great uncertainty. Suppressing spread of the virus was prioritised over other needs. Looking back, the benefits of the control measures did not always outweigh the harms, particularly in the situations of people with dementia and their care partners. Research is needed to better understand the impact of control measures to provide knowledge that policymakers can use to make better informed decisions in future crisis situations. In this report, we describe the research priorities people with dementia, their care partners and health care professionals for future research in this context, and translate their priorities into a research agenda.

The priorities identified by the three stakeholder groups partly overlapped, but also complimented each other. Despite marked differences in culture, lifestyles and health systems across the participating countries in this consortium, the current findings showed similarities across countries in priorities for future research and policy change. Therefore, the findings were combined into one research agenda.

The data presented in this report were collected in 14 countries (i.e. Brazil, Chili, Colombia, Ecuador, France, Greece, India, Ireland, Nepal, Netherlands, Nigeria, Peru, South Africa and UK) and across three stakeholder groups (i.e. people with dementia, their care partners and health care professionals). The priorities identified by the three stakeholder groups partly overlapped, but also complimented each other. Despite marked differences in culture, lifestyles and health systems across the participating countries in this consortium, the current findings showed similarities across countries in priorities for future research and policy change. Therefore, the findings were combined into one research agenda.

The priorities cluster together into four themes: physical health and daily routine, mental health, disease progression and carer impact. Across these four themes, three pillars were identified for future research. The first pillar, *mechanisms*, encourages research to understand how the control measures impacted on each theme. The second pillar, *interventions*, asks for research to develop and evaluate interventions to prevent or mitigate the negative effects of the control measures. The third pillar, *information and education*, was added as many participants expressed concerns about their health and wellbeing as a result of the pandemic and the control measures. Information and education play an important role in taking away those concerns. Finally, outcomes of the proposed research should be translated into (recommendations for) policy.

The goal of this research agenda is to provide overarching guidance for science funders and researchers on the key priorities for research in dementia, as defined by people with dementia, their care partners and health care professionals. Through this guidance, this research agenda encourages international alignment of research efforts to provide better care and support for people with dementia and their care partners in future crisis situations.

2. REPORT CONTEXT

Through the EU Joint Program for Neurodegenerative Disorders (JPND) and the Canadian Institutes of Health Research (CIHR, funding reference number: WGC 184304), we received funding to convene a consortium of professionals with interest in neurocognitive disorders from 14 countries (Appendix A) to ascertain research priorities regarding the impact of the COVID-19 restrictions on people with dementia living at home and their care partners. The consortium's findings will inform a research agenda. A research agenda sets clear goals for what program stakeholders want or need to know about a program of work for years into the future, by defining destination and identifying supporting steps to get there.

The goal of *this* research agenda is to provide overarching guidance for science funders and researchers on the key priorities for research in dementia, as defined by the stakeholders. Moreover, it can be used to initiate and enhance collaboration across stakeholder groups for the mobilisation of scientific knowledge and public health policy. In this project, stakeholders are people with dementia, informal care partners, health and social care professionals, advocates, and researchers in the field of dementia. This research agenda can be used to initiate and enhance collaboration across stakeholder groups for the mobilisation of scientific knowledge and public health policy.

This research agenda articulates research needs, focuses efforts, and directs research to learn from the impact of the COVID-19 pandemic on people with dementia and their care partners. While the initial crisis from the COVID-19 pandemic is over, many people are still feeling the consequences today. Experiences from the COVID-19 pandemic hold valuable information that can promote better societal preparedness for future pandemics or other crises. In this report, we define a 'crisis' as a large-scale unexpected event that leads to an unstable or high-risk situation affecting continuity of support for a community or society. Examples of crises are natural disasters, pandemics, or war. A crisis generally implies that change is required as the status quo cannot be maintained. Typically, in crisis situations, quick decisions need to be made in a context of great uncertainty around consequences of decisions. Hence, it is important to reflect on the COVID-19 pandemic, to learn from the experience and translate knowledge to recommendations for more suitable policy and support in future crisis situations.

The COVID-19 pandemic was global, but countries differed in the measures that were put in place to control spread of the virus. We adopted a 14-country perspective, including nations balanced across the global north and south. We believe that exchanging experiences across countries and regions is important to synthesise and accelerate research efforts. Setting research priorities further accelerates advancement by directing research efforts to areas where they are most urgently needed and have the greatest potential for impact.

Beneficiaries of this research agenda are:

- people living with dementia and their care partners;
- dementia advocates in third sector and other organisations;
- health and social care policy makers for dementia; and
- research and service development funders, including commissioners from the JPND and other national and international funding agencies.

3. INTRODUCTION

Globally, people with dementia and their care partners, particularly those living at home, were disproportionally affected by the COVID-19 pandemic. These individuals experienced significant negative impacts of COVID-19 control measures. For example, social restrictions (i.e., isolation and distancing) and reallocation of resources led to closure of support centres in many countries. Closure of these centres led to significant disruptions in daily routines and support (1), more rapid declines in physical and cognitive functioning, increase in behavioural problems and loneliness, deterioration in mental health and wellbeing (2, 3), and increased formal and informal care partner burden and stress (4). These negative impacts accumulated to a staggering 25% increase in the mortality risk among people living with dementia (5). In sum, almost every facet of COVID-19 statistics related to dementia have demonstrated the importance of equity considerations as key markers of difference, linked with social disparities that demand global attention and action.

During the peak of the pandemic, national and local governments were forced to make quick decisions to control the spread of the virus. The main control measures that were taken, included social distancing, isolation, hand hygiene, facial masks, and closure of public spaces. However, these decisions on control measures had to be made in the context great uncertainty. There was uncertainty around the behaviour of the virus itself, how long it would take to develop an effective vaccine, and the effectiveness and consequences of the control measures. Given the widespread impact of the control measures on all societal sectors, including health care, education and economy, policymakers faced significant challenges in weighing the consequences of measures across all sectors. In most cases, suppressing spread of the virus was prioritised over other needs, such as social connection. Looking back, the benefits of the control measures did not always outweigh the harms, particularly in the situations of people with dementia and their care partners.

Research is needed to better understand the impact of control measures to provide knowledge that policymakers can use to make more informed decisions in future crisis situations. To efficiently allocate funding resources, our consortium identified research priorities and concerns of people with dementia, their care partners, and health and social care professionals. This research agenda summarises evidence gaps and provides region-specific recommendations for solid research strategies to inform better care for people with dementia and their carers living at home, in the context of COVID-19 or in future pandemics or crises. We applied a regional focus with countries in Europe, South Asia, South America, and Sub-Saharan Africa.

4. INPUT FROM STAKEHOLDERS

Research priorities should be jointly identified by people with the lived experience, communities and healthcare professionals (6). To ensure that representatives of relevant stakeholder groups were consulted throughout the process, our consortium includes people with dementia, care partners, health care professionals, researchers and health policy experts, and advocates (Appendix A). Representatives were involved in all steps of the process and approved the final version of this report.

5. METHODS

Guided by James Lind Alliance methodology, three steps were taken to inform the research agenda. First, a broad *scoping literature review* was done to identify a wide range of potentially relevant topics from the perspective of people living with dementia and informal carers. Second, to narrow down the long list of potentially relevant topics to the top priorities per stakeholder subgroup and per country, a *priority setting process* was done using an online survey. Third, these top priorities were *translated to a research strategy*. Each of these steps is described in more detail below.

5.1 Literature review

A detailed description of the literature review will be published elsewhere (in progress). Briefly, using search terms for 'dementia' and 'COVID-19 control measures', we searched EMBASE, Web of Science, Medline, PsycINFO and CINAHL, covering the period March 2020 to July 2022. Studies were included if they reported results from original quantitative or qualitative studies examining the consequences of COVID-19 control measures on lives of people with dementia and their care partners. We were specifically interested in the outcomes of disease progression, physical health, mental health (including loneliness), access to care and health services and carer burden. No restrictions were used for language or country. Seventy papers were included, which describe data of over 260,000 people with dementia and care partners. From the extracted data, we derived a list of 72 topics, which was reduced to a condensed list of topics by merging topics that covered the same theme. This topic reduction was done by five researchers from the consortium through an iterative process that continued until the list was reduced to a maximum of 40 topics and consensus was reached.

5.2 Priority setting process

We conducted an online survey to prioritise the topics with the greatest impact on people with dementia and their care partners, and thus, which topics have highest priority to be addressed in research or policy. The online survey was a custom designed survey in which respondents were presented with the condensed list of 40 topics derived from the literature review. Respondents were asked to select a maximum of 10 topics that had the greatest impact on their lives during the COVID-19 pandemic. Next, respondents were given the opportunity to list any new topics in case we had missed something in the review of the literature. In the final step, respondents were asked to list their top 3 topics from the earlier list of 10 topics plus the additional topics. Respondents were also asked to indicate which control measure they found most difficult to deal with (multiple choice question) and describe what they would have liked to be different (open text question).

The survey also contained demographic questions for descriptive purposes. The survey was developed in English and finetuned based on feedback from representatives from all three stakeholder groups. The final version of the survey was translated into relevant languages. Open text responses were auto-translated to English and checked by the researcher from the relevant countries for accuracy.

Our aim was to recruit 20 respondents per country, ideally a combination of people with dementia, care partners and health and social care professionals. In some countries ethical restrictions or practical circumstances did not allow us to recruit people with dementia. Ethical clearance was required in some, but not all countries. For country specific details, please refer to the Appendix D.

5.3 Translating research priorities to a research strategy

First, the survey responses were summarized into country-specific lists of top 10 priorities. These lists were produced separately for people with dementia, care partners and care professionals to see if preferences differed for these stakeholder groups. The ranking of topics was decided on by assigning 1 point each time a topic was selected in the top 10 list and an extra point each time a topic was also selected in the top 3 list. The 10 topics with the highest total rank were included in the priority lists.

Second, generic priority lists were formed by adding up the rankings of all countries. For each of the three stakeholder groups, a generic list was only created if there was sufficient overlap between priority lists of the countries. These generic lists were then translated into a research strategy. This was initially done by a subgroup of the consortium. The initial list of priorities and research strategy were then shared with the full consortium for feedback and amended via iterative rounds of videocalls until consensus was reached.

Third, for each country, the country-specific priority lists were compared with the generic priority lists. In consultation with the researchers of that country, we decided whether any deviations from the generic list were needed, or whether there were specific conditions that need to be considered for that country, for example, given the specifics of the health system or cultural context.

6. RESULTS

6.1. Results literature review

Results from the literature review will be described in detail elsewhere (in progress). Briefly, in total, 70 papers were included, which describe data of over 260,000 people with dementia and care partners. From the extracted data, we derived a list of 72 topics covering the following themes: physical health/daily functioning, cognition, mental health, behavioural problems, wellbeing, access to health services, health and wellbeing of the care partner, and care burden. This list was reduced to a condensed list of 39 topics by merging topics that covered the same theme (Appendix B).

6.1.1 Results priority setting process

The data presented in this report were collected in 14 countries, i.e. Brazil, Chili, Colombia, Ecuador, France, Greece, India, Ireland, Nepal, Netherlands, Nigeria, Peru, South Africa and UK.

In total, 256 people completed the STRAP survey: 29 people with dementia, 110 care partners and 117 care professionals completed the survey (Table 1). People with dementia who responded to the survey were mostly over the age of 65 years with Alzheimer type dementia (Table 2). Care partners who responded to the survey were predominantly female with all age-categories represented (Table 3). The care professionals who responded were also predominantly women across al countries (Table 4).

As there was substantial overlap between the priority lists of the countries (Appendix C), the overall results are presented here. Country specific results are provided in Appendix D.

Table 1. Number of respondents per stakeholder group per country

	Total	People with dementia	Care partners	Care professionals
Brazil	18	2	12	4
Chile	17	1	15	1
Colombia	6	0	0	6
Ecuador	25	0	4	21
France	9	0	3	6
Greece	25	0	15	10
India	12	0	9	3
Ireland	20	4	9	7
Nepal	12	0	4	8
Netherlands	17	0	7	10
Nigeria	24	8	6	10
Peru	20	7	7	6
South Africa	16	0	8	8
UK	16	6	1	9
Unknown/non-participating country	19	1	10	7
Total	256	29	110	117

Table 2. Characteristics of people with dementia who responded to the survey

	Brazil	Chile	Colombia	Ecuador	France	Greece	India	Ireland	Nepal	Netherlands	Nigeria	Peru	South Africa	UK
N	2	1	0	0	0	0	0	4	0	0	8	7	0	6
Age (%)														
<45 yrs	0	0	n/a	n/a	n/a	n/a	n/a	0	n/a	n/a	0	0	n/a	0
45-54 yrs	0	0	n/a	n/a	n/a	n/a	n/a	0	n/a	n/a	0	0	n/a	16.7
55-64 yrs	0	0	n/a	n/a	n/a	n/a	n/a	100	n/a	n/a	0	14.3	n/a	50.0
65-74 yrs	100	0	n/a	n/a	n/a	n/a	n/a	0	n/a	n/a	62.5	42.9	n/a	16.7
75+ yrs	0	100	n/a	n/a	n/a	n/a	n/a	0	n/a	n/a	37.5	42.9	n/a	16.7
Gender (%)														
Women	50.0	100	n/a	n/a	n/a	n/a	n/a	25.0	n/a	n/a	25.0	42.9	n/a	16.7
Men	50.0	0	n/a	n/a	n/a	n/a	n/a	50.0	n/a	n/a	62.5	57.1	n/a	66.7
Prefer not to say	0	0	n/a	n/a	n/a	n/a	n/a	25.0	n/a	n/a	12.5	0	n/a	0
Not answered	0	0	n/a	n/a	n/a	n/a	n/a	0	n/a	n/a	0	0	n/a	16.7
Managing on income (%)														
Very difficult	0	0	n/a	n/a	n/a	n/a	n/a	25.0	n/a	n/a	0	14.3	n/a	66.7
Somewhat difficult	0	0	n/a	n/a	n/a	n/a	n/a	25.0	n/a	n/a	37.5	57.1	n/a	0
Not easy/not difficult	0	100	n/a	n/a	n/a	n/a	n/a	25.0	n/a	n/a	0	0	n/a	16.7
Somewhat easy	0	0	n/a	n/a	n/a	n/a	n/a	0	n/a	n/a	25.0	28.6	n/a	0
Very easy	100	0	n/a	n/a	n/a	n/a	n/a	25.0	n/a	n/a	25.0	0	n/a	0
Not answered	0	0	n/a	n/a	n/a	n/a	n/a	0	n/a	n/a	12.5	0	n/a	16.7
Type of dementia (%)														
Alzheimer disease	n/a	n/a	n/a	n/a	n/a	n/a	n/a	0	n/a	n/a	87.5	85.7	n/a	66.7
Vascular dementia	n/a	n/a	n/a	n/a	n/a	n/a	n/a	0	n/a	n/a	12.5	0	n/a	0
Lewy Body dementias	n/a	n/a	n/a	n/a	n/a	n/a	n/a	50.0	n/a	n/a	0	0	n/a	0
FTD	n/a	n/a	n/a	n/a	n/a	n/a	n/a	0	n/a	n/a	0	14.3	n/a	16.7
Other/unknown	0	0	n/a	n/a	n/a	n/a	n/a	25.0	n/a	n/a	0	0	n/a	16.7
Prefer not to say	0	0	n/a	n/a	n/a	n/a	n/a	25.0	n/a	n/a	0	0	n/a	0

AD Alzheimer Disease; FTD Frontotemporal dementia; n/a not applicable as no people with dementia responded in this country

Table 3. Characteristics of care partners who responded to the survey

	Brazil	Chile	Colombia	Ecuador	France	Greece	India	Ireland	Nepal	Netherlands	Nigeria	Peru	South Africa	UK
N	12	15	0	4	3	15	9	9	4	7	6	7	8	1
Age (%)														
<45 yrs	0	6.7	n/a	100	0	20.0	55.6	0	25.0	0	0	0	12.5	0
45-54 yrs	16.7	53.3	n/a	0	0	33.3	11.1	11.1	25.0	28.6	0	14.3	12.5	100
55-64 yrs	41.7	13.3	n/a	0	0	33.3	11.1	55.6	25.0	57.1	0	42.9	37.5	0
65-74 yrs	33.3	13.3	n/a	0	66.7	0	22.2	11.1	25.0	14.3	0	28.6	25.0	0
75+ yrs	0	13.3	n/a	0	33.3	0	0	0	0	0	0	0	12.5	0
Not specified	8.3	0	n/a	0	0	13.3	0	22.2	0	0	100	14.3	0	0
Gender (%)														
Women	83.3	86.7	n/a	75.0	66.7	66.7	44.4	100	75.0	85.7	33.3	71.4	87.5	0
Man	16.7	13.3	n/a	25.0	33.3	20.0	55.6	0	25.0	14.3	50.0	28.6	12.5	100
Prefer not to say	0	0	n/a	0	0	13.3	0	0	0	0	0	0	0	0
Not answered	0	0	n/a	0	0	0	0	0	0	0	16.7	0	0	0
Managing on income (%)														
Very difficult	16.7	58.3	n/a	25.0	0	20.0	11.1	22.2	0	0	16.7	0	37.5	0
Somewhat difficult	33.3	33.3	n/a	75.0	0	33.3	33.3	33.3	0	0	0	71.4	37.5	0
Not easy/not difficult	16.7	8.3	n/a	0	33.3	20.0	11.1	33.3	75.0	42.9	50.0	0	25.0	100
Somewhat easy	16.7	0	n/a	0	0	6.7	22.2	11.1	25.0	57.1	0	14.3	0	0
Very easy	16.7	0	n/a	0	66.7	20.0	22.2	0	0	0	16.7	14.3	0	0
Not answered	0	0	n/a	0	0	0	0	0	0	0	16.7	0	0	0
Type of dementia (%)														
Alzheimer disease	91.7	46.7	n/a	25.0	33.3	20	55.6	25	75.0	0	0	71.4	37.5	0
Vascular dementia	0	13.3	n/a	0	33.3	13.3	0	25	0	33.3	0	0	12.5	100
Lewy Body dementias	0	6.7	n/a	0	0	0	0	12.5	0	16.7	0	0	0	0
FTD	0	6.7	n/a	0	0	6.7	44.4	0	0	33.3	0	28.6	0	0
Other/unknown	0	20	n/a	75.0	0	46.7	0	12.5	25.0	16.7	0	0	50.0	0
Not specified	8.3	6.7	n/a	0	33.3	13.3	0	25	0	0	100	0	0	0

AD Alzheimer Disease; FTD Frontotemporal dementia; n/a not applicable as no care partners responded in this country

Table 4. Characteristics of care professionals who responded to the survey

	Brazil	Chile	Colombia	Ecuador	France	Greece	India	Ireland	Nepal	Netherlands	Nigeria	Peru	South Africa	UK
N	4	1	6	21	6	10	3	7	8	10	10	6	8	9
Gender (%)														
Women	100	100	83.3	66.7	100	60.0	33.3	42.9	75.0	100	40.0	83.3	87.5	77.8
Men	0	0	16.7	23.8	0	40.0	33.3	28.6	25.0	0	60.0	16.7	12.5	22.2
Prefer not to say	0	0	0	9.5	0	0	33.3	28.6	0	0	0	0	0	0
Managing on income (%)														
Very difficult	0	0	0	33.3	0	20.0	0	14.3	75.0	0	20.0	0	25.0	0
Somewhat difficult	0	100	16.7	28.6	0	30.0	0	14.3	0	0	0	33.3	12.5	0
Not easy/not difficult	50	0	50	28.6	0	40.0	33.3	0	12.5	20	60.0	33.3	25.0	75.0
Somewhat easy	0	0	0	4.8	50.0	0	66.7	42.9	12.5	30	20.0	33.3	25.0	25.0
Very easy	50	0	33.3	4.8	50.0	10.0	0	28.6	0	30	0	0	12.5	0
Not answered	0	0	0	0	0	0	0	0	0	20	0	0	0	0

n/a not applicable as no care professionals responded in this country

6.2.1 Research priorities chosen by people with dementia

Figure 1 shows the research priorities chosen by people with dementia. These results show that people with dementia were particularly concerned about the impact of the control measures on the disruption in their daily routines (i.e. sleep, eating pattern, and social activities) and the subsequent impact on disease progression and overall physical and mental health.

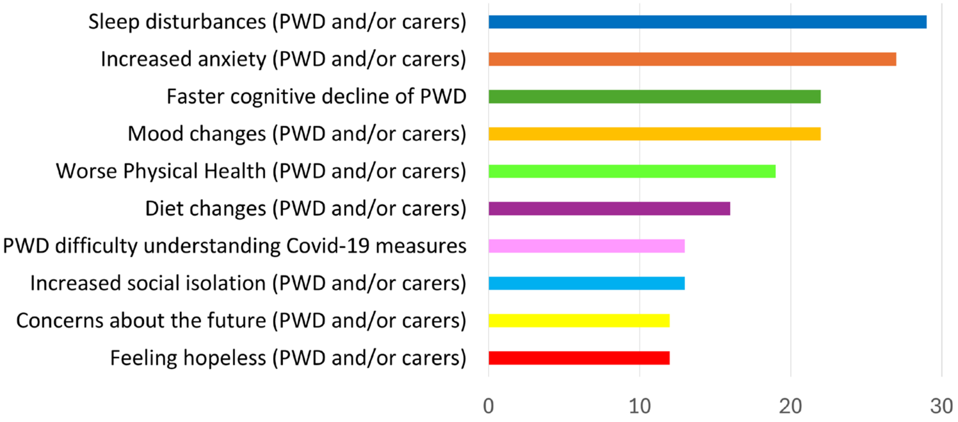


Figure 1. Top 10 priorities for people with dementia.
X-axis = number of votes; PWD = people with dementia; carers = care partners

6.2.2 Research priorities chosen by care partners

Figure 2 shows the research priorities chosen by care partners. These results show that care partners were mostly concerned about disease progression and mental and physical health of the person with dementia. They also struggled with dealing with the person with dementia not understanding the situation and need for control measures. Moreover, having to deal with the control measures (e.g. maintaining hygiene and distance) and the consequences of the control measures (e.g. closure of day care centres) further added to the care responsibilities and perceived care burden.

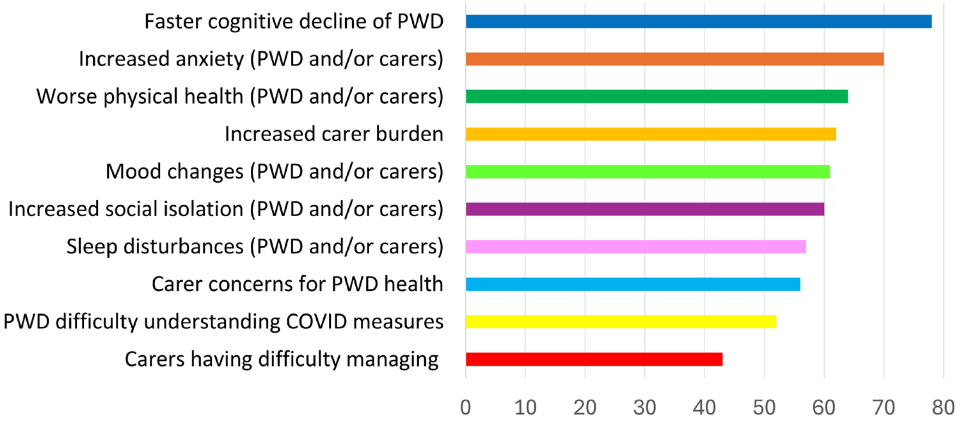


Figure 2. Top 10 priorities for care partners
X-axis = number of votes; PWD = people with dementia; carers = care partners

6.2.3 Research priorities chosen by care professionals

Figure 3 shows the priorities chosen by care professionals. These results show that care professionals felt that people with dementia were mostly impacted by the control measures in terms of accelerated disease progression and worsening of physical and mental health, possibly due to social isolation. They also worried about the impact of control measures on the care burden for the care partners exacerbated by the control measures and difficulty in accessing medical support.

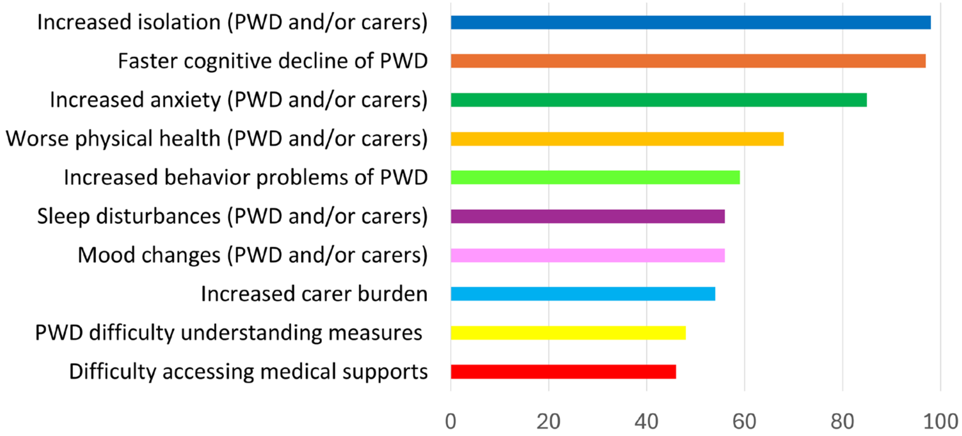


Figure 3. Top 10 priorities for care professionals
X-axis = number of votes; PWD = people with dementia; carers = care partners

6.3 The research strategy

Given the large degree of overlap in prioritised topics across the three stakeholder groups (Appendix C), we decided to combine these topics into one overall list of 12 priorities. These priorities cluster into four themes, which are: physical health and daily routine, mental health, disease progression and carer impact (Figure 4).

Initially, our aim was to formulate specific research questions for each prioritised topic. However, as the gap in knowledge is large and these topics reflect broad themes rather than specific questions, we decided it was more appropriate and informative to provide broad directions for future research rather than specific research questions. Looking at the prioritised research topics, the consortium discussed which levels of knowledge were required to address the topics.
A consensus fell on three pillars that are relevant for all prioritised topics:
1. mechanisms (i.e. how the impact occurred);
2. interventions;
3. education and information.
These pillars for research focus cut across all four themes and together form a matrix that summarizes the research strategy (Figure 4). Ultimately, outcomes of the proposed research should inform policy.

Pillar 1: Mechanisms of how the COVID-19 pandemic impacted people with dementia
Within each theme and for each prioritised topic, research is needed to understand how the control measures impacted on that topic. A better understanding of such mechanisms is needed to be able to develop effective interventions. Key questions include:

- *What were the mechanisms driving the impact of the control measures?*
- *What were potential protective or aggravating factors that modified the impact of the control measures?*

For example, for the topic of sleep, specific research questions may be ‘Were sleeping problems more pronounced during lockdowns than before or after lockdowns?’, ‘Could reduced sleep quality be explained by the disruption in daily routine?’ and ‘What factors mitigate the negative effect of the lockdown on sleep?’

As the peak of the COVID-19 pandemic is behind us and control measures are no longer needed on a public scale, prospective studies to examine such mechanisms are no longer possible. However, during the pandemic, many data were collected, also in the context of ongoing cohort studies and registries. These data are particularly valuable in unravelling these mechanisms, for example, by comparing pre-, peri- and post-pandemic trends. As regions or countries differed in the types of control measures that were put in place, region or country comparisons may be useful in understanding the impact of specific (intensities or combinations) of control measures. Data portals that facilitate data sharing and harmonisation could foster cross-country/region comparisons and enhance use of available data.

Pillar 2: Interventions to support people with dementia and care partners
Once the mechanisms are clear, this knowledge can be used to develop solutions to avoid or mitigate the negative effects of a pandemic or other crisis. Key questions include:

- *How should control measures be adapted to suit the situation of people with dementia and their care partners?*
- *How can benefits and harms of control measures best be monitored in future crisis situations?*

Ideally, the effectiveness of these solutions should be evaluated. However, in absence of a crisis this may not be possible on a large scale, while in the presence of a crisis this may not be feasible. Therefore, alternate forms of evaluation should be considered, for example in the situation of a small crisis or situations that mimic crisis situations. One such situation may be the care for a person with dementia who needs to be in contact isolation due to an infectious disease. Another option is to use data from intervention studies with data collected in pre-, peri- and post-lock down periods and compare the magnitude of the effect of the intervention in the different periods to evaluate if those interventions could mediate the impact of the pandemic on the outcomes (see for example (7)).

Pillar 3: Education & information about dementia in a time of crisis
Lack of information and uncertainty about the future was a recurring theme in the qualitative studies included in the literature review. Although this topic did not make it into the final priority list, it did ring through in topics that were selected. Better communication about available support, future expectations and duration of lock downs may prevent or reduce feelings of hopelessness and concerns about the future. Information and education play an important role in taking away the concerns that were prioritised. Uncertainty about the future is a key feature of crisis situations, so it will be difficult to fully avoid this issue. However, knowledge gained from past crises can help to inform better responses in future crises. Key questions include:

- *What are effective methods for communication in times of crisis for people with dementia and their care partners?*
- *What information needs do people with dementia and their care partners have in times of crisis?*

Concerns about accelerated cognitive decline was one of the top rated priorities (Figures 1-3). However, studies that evaluated pre-lockdown cognition with peri-lockdown cognition found no evidence for accelerated decline in cognitive functioning taking into account natural progression. Such information may be used to reassure concerned people with dementia and carers.

Research may focus both on what information or educational resources to provide, and how to provide it. During the COVID-19 pandemic, many care professionals switched from in person care to telemedicine. It may be informative to evaluate how this support was received, how it could be improved, what other forms of communication would be useful, and how groups who do not have access to telemedicine can be reached.

Translation of results from the research strategy into policy
Outcomes of the proposed research should be translated into (recommendations for) policy. To continuously learn from future crisis situations and iteratively improve the policy, it is also important to monitor impact of policy changes. Key questions here are:

- *How can policy makers weigh up the benefits and harms of control measures in future pandemics or crisis situations?*
- *How can the impact of policy changes be monitored?*

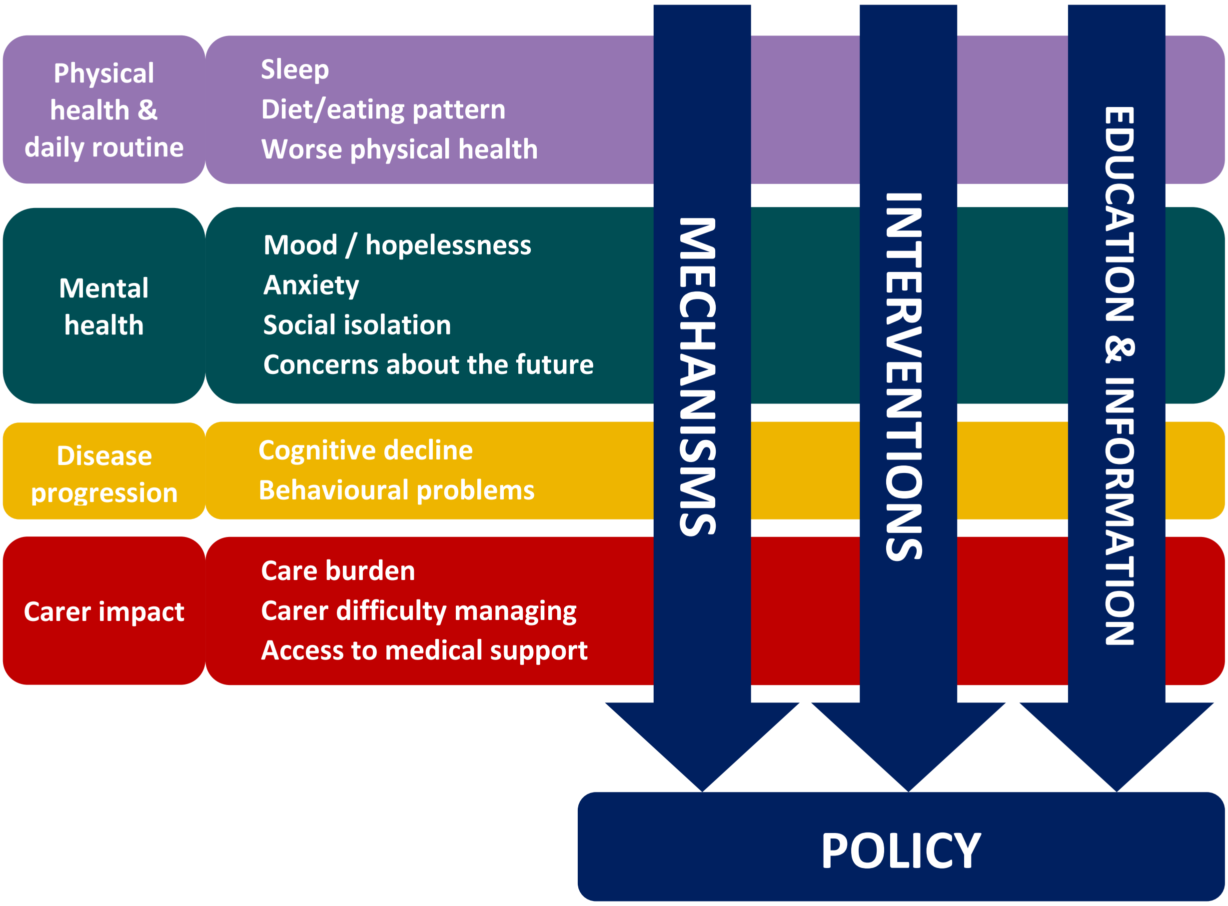


Figure 4. Matrix summarizing research strategy according to chosen priorities and overarching themes mechanisms

7. REFLECTIONS AND RECOMMENDATIONS

The data presented in this report were collected in 14 countries. i.e. Brazil, Chili, Colombia, Ecuador, France, Greece, India, Ireland, Nepal, Netherlands, Nigeria, Peru South Africa. and UK. Given the consistency in findings across these countries, we decided to establish one generic list of priorities and one generic research agenda. Deviations from the generic list of priorities are discussed in the country-specific reflections in Appendix D. Representatives from all countries (Appendix A) have endorsed this report and the proposed research agenda.

During the COVID-19 pandemic, policy makers prioritised suppressing spread of the virus over other needs. Looking back, the benefits of the control measures did not always outweigh the harms. The findings from the survey reinforce this. The findings indicate that people want measures that protect routine, mental health and social connection, and that minimize care burden.

In the priority setting process, we utilised elements from the James Lind Alliance protocol (8). Due to feasibility issues around limited time and resources, it was not possible to follow all the protocolised steps. Ideally, the priority setting process includes a survey to collect input from a representative group of stakeholders, which is followed by a focus group to finetune and decide on the final set of priorities. Given the many countries and languages involved, a single focus group in which stakeholders from each country are represented would not have been appropriate. Importantly, the content of the survey was based on outcomes of the literature review, which included qualitative and quantitative data from over 260,000 people with dementia and informal care partners from around the world, including the regions which participated in this project. Another strength of our approach was that the survey was translated from English into 7 other languages so that it could be conducted in 14 countries. In addition to the priority setting, the survey also provided an opportunity for stakeholders to list additional topics. While additional topics were suggested, these all fitted within the constructs of existing topics. Hence, we are confident that the most important topics and themes were identified.

There is an urgency for funding agencies and researchers to act towards the proposed research agenda. As a society we must optimally benefit from the experiences of the COVID-19 pandemic. Time changes our perspectives on what happened during that pandemic. Our memories fade and our attention turns to current challenges. With that, also the sense of urgency to act fades. The COVID-19 pandemic showed us that, as a society, we were not prepared for a pandemic of this size. As we never know when a next pandemic may occur, we must act now to be better prepared for the next pandemic.

Box 1 summarises recommendations for funding agencies, researchers and policy makers which were informed by the work done to develop this research agenda as well as discussions within the consortium. These recommendations are described in more detail in section 6.3. Funding agencies may encourage international collaboration, co-creation with stakeholders and the use of creative study designs by incorporating conditions for funding and quality criteria in funding calls. Researchers can use these recommendations to strengthen their study designs. Policy makers have a role in providing required supporting infrastructure as well as being an active partner in the translation and implementation of findings into policy.

BOX 1. Recommendations for funding agencies, researchers, and policy makers

- Fund research on items listed on the proposed research agenda to ensure better crisis-preparedness (pillars 1-3)..
- Aim for smart use of available data: use existing sources if available and facilitate data portals for data sharing and harmonisation. Resort to collection of new data only if research questions cannot be answered with available data. (pillars 1 & 2).
- Encourage International collaboration to optimally benefit from exchange of knowledge and capacity building, as different countries have different levels of experience in responding to crisis situations (pillars 1-3).
- Encourage International comparisons to provide unique knowledge on the impact of different combinations of control measures (pillar 1).
- Stimulate co-creation with stakeholders in Intervention design and education strategies to optimise the implementation success (pillar 2-3).
- Stimulate creative study designs in the evaluation of effectiveness of interventions (pillar 2).

APPENDIX A: THE STRAP CONSORTIUM

This research agenda has been written as a joint effort by the STRAP consortium, formed by researchers, clinicians, and public and patient representatives from 14 countries, with contributions from:

Brazil: Paulo Caramelli, Elisa de Paula França Resende*, Faculdade de Medicina and Hospital das Clínicas, Universidade Federal de Minas Gerais, Belo Horizonte, Brazil

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France: Yaohua Chen*, University of Lille, Lille, France

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India: Suvarna Alladi, Faheem Arshad* and Aparna Somaraj, National Institute of Mental Health and Neurosciences, Bangalore, India

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Nigeria: Adesola Ogunniyi* and Rufus Akinyemi*, University of Ibadan, Ibadan; Temitope Farombia, University College Hospital, Ibandan

South Africa: Khanyo Ntocozo Ngcobo, Kwazulu Natal, South Africa

Romania: Stefania Ilinca*, European Centre for Social Welfare Policy and Research, Vienna;

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APPENDIX B: TOPICS LIST

The below table presents the list of 72 topics derived from the literature review. From this list, a condensed list of 38 topics was selected for inclusion in the survey.

N	Original List of Priorities	Reduced List
1	Diet/appetite changes	Diet or appetite changes of people with dementia and/or informal carers
2	Sleep disturbances of carer	Sleep disturbances for people with dementia and/or informal carers
3	Sleep disturbances of PWD	
4	Increased use/dose of medications	Increased use/dose of medications by person with dementia
5	Weight change	Worsening physical health of people with dementia and/or informal carer
6	Poorer physical health	
7	Increased incontinence	
8	Worsening mobility/motor functions	
9	Fatigue	
10	Faster cognitive decline	Faster cognitive decline of person with dementia
11	Difficulties understanding situation	Person with dementia has difficulties understanding the COVID-19 situation
12	Difficulty managing control measures in context of patients not understanding	Informal carers have difficulty managing COVID-19 control measures in context of people with dementia not understanding the situation
13	Worsening psychological symptoms	
14	Increased anxiety/stress	Increased anxiety/stress of people with dementia and/or informal carers
15	Fear of covid infection	
16	fears of infecting caree	
17	Feeling of never endless pandemic	People with dementia and/or informal carers feeling hopeless (e.g., feeling discouraged, loss of purpose, feeling the pandemic will never end)
18	Feeling hopeless	
19	Grief	Experiencing grief (people with dementia and/or informal carers)
20	Mood changes	Mood changes of people with dementia and/or informal carers (e.g., increased depression, sadness, mood swings)
21	concerns about health of patient	Concerns about health of person with dementia
22	worries of worsening dementia of patient	
23	concerns about health of carer	Concerns about health of informal carer
24	concerns about health of family/friends	Person with dementia and/or informal carer concerns about health of family and friends
25	Carer fear of struggling to cope	Informal carer fears of struggling to cope due to COVID-19 measures
26	Fear of reduced support	
27	fears/concerns about the future	Person with dementia and/or informal carer concerns about the future
28	concerns about leaving the house	
29	More behavioural problems	Increased behavioural problems of people with dementia
30	Higher/increased loneliness	
31	Isolation	Increased social isolation of people with dementia and/or informal carers

32	Decreased quality of life	Changes in quality of life and/or life satisfaction (positive/negative) of people with dementia and/or informal carers
33	Decreased life satisfaction	
34	Increased care burden/responsibilities	Increased care burden and/or care responsibilities of informal carer due to COVID-19 measures
35	Struggling to cope	Positive/negative coping strategies used by people with dementia and/or informal carers
36	Dysfunctional coping strategies	
37	Beneficial coping strategies	
38	Change in quality of relationship between CR and caregiver	Changes (positive/negative) in the quality of relationships for people with dementia and/or informal carers
39	Increased family Issues	
40	Not able to use technologies	
41	not satisfied with technology	
42	Regular telephone calls to friends	Changes (positive/negative) in social contacts of people with dementia and/or informal carers
43	Need of connection with other carers	
44	Changes in social contacts	
45	Increased stigma	Increased stigma experienced by informal carers during COVID-19 pandemic
46	Loss/change of/in work	Loss of work/change in work of informal carers due to COVID-19 measures
47	Loss/interruption of physical activities	Interruption of physical and/or social activities of people with dementia and/or informal carers
48	Loss of routine	
49	New rules and restrictions	
50	Financial uncertainties/difficulties	Financial uncertainties/difficulties for people with dementia and/or informal carers
51	concerns about financial security due to covid	
52	Increased care time	Increased time informal carers spend caring for person with dementia
53	Lack of respite time	
54	Reduced personal care	People with dementia having reduced personal care
55	Needs vary per person, depending on personal situation	
56	Emergence of new care needs	
57	Guilt among family around being unable to visit carees	Informal carers experiencing guilt over not being able to visit person with dementia
58	Difficulties in accessing basic needs	Difficulty in accessing basic needs (e.g., difficulty going shopping, difficulties accessing care, etc.)
59	Loss of formal home care service	
60	Discontinuation/shut down of services	Discontinuation/shut down of services (e.g., appointments, doctor visits, etc.)
61	Lack of access to medical support	Lack of access to medical support
62	Alternative care/support methods	
63	Increased cost of care	Increased cost of care
64	Increased inequalities that existed before Covid	Increased inequities that existed before COVID-19

65	Avoiding seeking help for health issues	People with dementia and/or informal carers avoiding seeking help for health issues out of fear of getting COVID-19 in hospitals or doctor surgeries
66	Introversion/avoidance	
67	Children of caree taking over carer role	
68	Reduced friend/family support	Reduced support for people with dementia and/or informal carers
69	Need/want more support	
70	Unable to stay during hospitalization for carers	
71	Loss of independency	
72	Lack of information	Lack of information on what supports and services were available for people with dementia and/or their informal carers during the COVID-19 pandemic

APPENDIX C: OVERVIEW OF PRIORITIES AND OVERLAP ACROSS STAKEHOLDER GROUPS

	Overall			
	Overall	PWD	Carer	Professional
Diet or appetite changes of PWD and/or CP	89	16	38	35
Sleep disturbances for PWD and/or CP	142	29	57	56
Worsening physical health of PWD and/or CP	151	19	64	68
Faster cognitive decline of PWD	197	22	78	97
Increased use/dose of medications by PWD	47	8	11	28
PWD has difficulty understanding the COVID-19 situation	113	13	52	48
CP have difficulty managing COVID-19 control measures in context of PWD not understanding the situation	85	3	43	39
Increased anxiety/stress of PWD and/or care partners	182	27	70	85
PWD and/or CP feeling hopeless (e.g., feeling discouraged, loss of purpose, feeling the pandemic will never end)	74	12	23	39
Mood changes of PWD and/or CP (e.g., increased depression, sadness, mood swings)	139	22	61	56
Experiencing grief (PWD and/or CP)	55	6	10	39
Concerns about health of PWD	98	9	56	33
Concerns about health of CP	51	1	33	17
PWD and/or CP concerns about health of family and friends	12	4	3	5
CP fears of struggling to cope due to COVID-19 measures	34	1	17	16
PWD and/or CP concerns about the future	46	12	17	17
Increased behavioural problems of PWD	111	11	41	59
Increased social isolation of PWD and/or CP	171	13	60	98
Changes in quality of life and/or life satisfaction of PWD and/or CP	83	8	41	34
Increased care burden and/or responsibilities of CP	119	3	62	54
Positive/negative coping strategies used by PWD and/or CP	32	2	14	16
Changes in the quality of relationships for PWD and/or CP	47	6	22	19
Changes in social contacts of PWD and/or CP	58	3	34	21
Increased stigma experienced by CP during COVID-19 pandemic	7	0	1	6
Loss of work/change in work of CP due to COVID-19 measures	34	1	20	13
Interruption of physical and/or social activities of PWD and/or CP	57	3	25	29
PWD having reduced personal care	39	4	17	18
Increased time CP spend caring for person with dementia	46	1	28	17
Financial uncertainties/difficulties for PWD and/or CP	53	9	32	12
CP experiencing guilt over not being able to visit PWD	22	2	8	12
Difficulty in accessing basic needs (e.g., shopping, accessing care)	51	6	19	26
Discontinuation/shut down of services (e.g. doctor visits)	74	7	27	40
Lack of access to medical support	68	6	16	46
Increased cost of care	34	2	16	16
Reduced support for PWD and/or CP	62	3	25	34
Increased inequities that existed before COVID-19	20	0	4	16
PWD and/or CP avoiding seeking help for health issues out of fear of getting COVID-19 in hospitals or doctor surgeries	65	11	17	37
Lack of information on what supports and services were available for PWD and/or CP during the COVID-19 pandemic	64	3	38	23

CP Care partner; PWD person with dementia

Highlighted in yellow are the topics with the most votes within that stakeholder group

APPENDIX D: COUNTRY SPECIFIC RESULTS

D.1 Brazil

In Brazil, the survey was approved by the local University Ethics Committee. The Portuguese version of the survey was distributed through social media channels and mailing lists of the Universidade Federal de Minas Gerais, in Belo Horizonte. Although all three stakeholder groups were invited to participate, only 2 people with dementia responded to the survey. In addition, 12 care partners and 4 care professionals responded to the survey.

Table 2 shows that there is substantial overlap between the topics that received the most votes from the Brazilian respondents and the generic list. Worsening physical health and faster cognitive decline were the most important aspects related to the pandemic across all the groups of people with dementia, care partners and care professionals. For the care partners, stress and difficulties of the person with dementia understanding the situation were the most important topics, suggesting they were suffering a high care burden during the pandemic. Two topics that were prioritised in Brazil, but not included in the generic list, were ‘changes in quality of life’ and ‘changes in the quality of relationship’. These topics may warrant extra attention in Brazil, in addition to the research agenda as described above.

Table 5. Number of times a topic was prioritised in Brazil compared with the generic list

	Generic List	Brazil			
		Overall	PWD	Carer	Professional
Diet or appetite changes of PWD and/or CP	89	0	0	0	0
Sleep disturbances for PWD and/or CP	142	5	0	5	0
Worsening physical health of PWD and/or CP	151	11	0	7	4
Faster cognitive decline of PWD	197	16	2	9	5
Increased use/dose of medications by PWD	47	1	0	1	0
PWD has difficulty understanding the COVID-19 situation	113	7	0	7	0
CP have difficulty managing COVID-19 control measures in context of PWD not understanding the situation	85	6	0	4	2
Increased anxiety/stress of PWD and/or care partners	182	10	0	7	3
PWD and/or CP feeling hopeless (e.g., feeling discouraged, loss of purpose, feeling the pandemic will never end)	74	4	0	3	1
Mood changes of PWD and/or CP (e.g., increased depression, sadness, mood swings)	139	7	2	4	1
Experiencing grief (PWD and/or CP)	55	1	0	1	0
Concerns about health of PWD	98	11	0	10	1
Concerns about health of CP	51	7	0	7	0
PWD and/or CP concerns about health of family and friends	12	3	0	3	0
CP fears of struggling to cope due to COVID-19 measures	34	4	0	4	0
PWD and/or CP concerns about the future	46	2	1	1	0
Increased behavioural problems of PWD	111	11	0	5	6
Increased social isolation of PWD and/or CP	171	11	2	6	3
Changes in quality of life and/or life satisfaction of PWD and/or CP	83	5	2	3	0
Increased care burden and/or responsibilities of CP	119	15	1	10	4
Positive/negative coping strategies used by PWD and/or CP	32	1	0	1	0
Changes in the quality of relationships for PWD and/or CP	47	5	2	3	0
Changes in social contacts of PWD and/or CP	58	4	0	4	0
Increased stigma experienced by CP during COVID-19 pandemic	7	1	0	0	1
Loss of work/change in work of CP due to COVID-19 measures	34	3	0	0	3
Interruption of physical and/or social activities of PWD and/or CP	57	10	2	6	2
PWD having reduced personal care	39	2	0	2	0
Increased time CP spend caring for person with dementia	46	5	0	4	1
Financial uncertainties/difficulties for PWD and/or CP	53	4	0	1	3
CP experiencing guilt over not being able to visit PWD	22	1	1	0	0
Difficulty in accessing basic needs (e.g., shopping, accessing care)	51	5	0	3	2
Discontinuation/shut down of services (e.g., appointments, doctor visits)	74	5	1	1	3
Lack of access to medical support	68	1	0	1	0
Increased cost of care	34	0	0	0	0
Reduced support for PWD and/or CP	62	5	0	3	2
Increased inequities that existed before COVID-19	20	4	0	1	3
PWD and/or CP avoiding seeking help for health issues out of fear of getting COVID-19 in hospitals or doctor surgeries	65	5	1	3	1
Lack of information on what supports and services were available for PWD and/or CP during the COVID-19 pandemic	64	6	0	6	0

CP Care partner; PWD person with dementia

Highlighted in yellow are the topics with the most votes within that stakeholder group

D.2 CHILE

In Chile, the survey was approved by the “Servicio de Salud Metropolitano Sur Oriente” Ethics Committee at August 8 th 2023. The spanish version of the survey was revised by Dr Leon and then distributed through social media channels and networks lists of the Centro de Memoria y Neuropsiquiatría (CMYN) of the Hospital del Salvador in Santiago. Although all three stakeholder groups were invited to participate, only 1 person with dementia and 1 care professional responded to the survey. In total, 15 care partners responded to the survey. CMYN has a strong care partners support group that stays connected after the post-diagnosis program at CMYN. Most of the care partners who participated came from that group.

Its noteworthy that the Chilean sample of care partners is younger than other countries (except the UK). This may partially explain why the Chilean sample was the one who manifested more difficulties in managing on income, as this group faces a major loss of job and financial opportunities due to the caregiving duties and are in need of more support.

Table 2 shows that there is substantial overlap between the topics that received the most votes from the Chilean respondents and the generic list. The most important consequences of the control measures for the Chilean sample related to the health of the person with dementia, including worsening of their physical health, cognitive status and behavioural symptoms. For the care partners, the major issue was increased care burden. Topics that were prioritised in Chile, but not included the generic list, were ‘Increased use/dose of medications by person with dementia’ and ‘experiencing grief’. The increased medication likely relates to the worsening of health. Experiencing grief is a topic that may need extra attention in Chili compared in addition to the proposed research agenda.

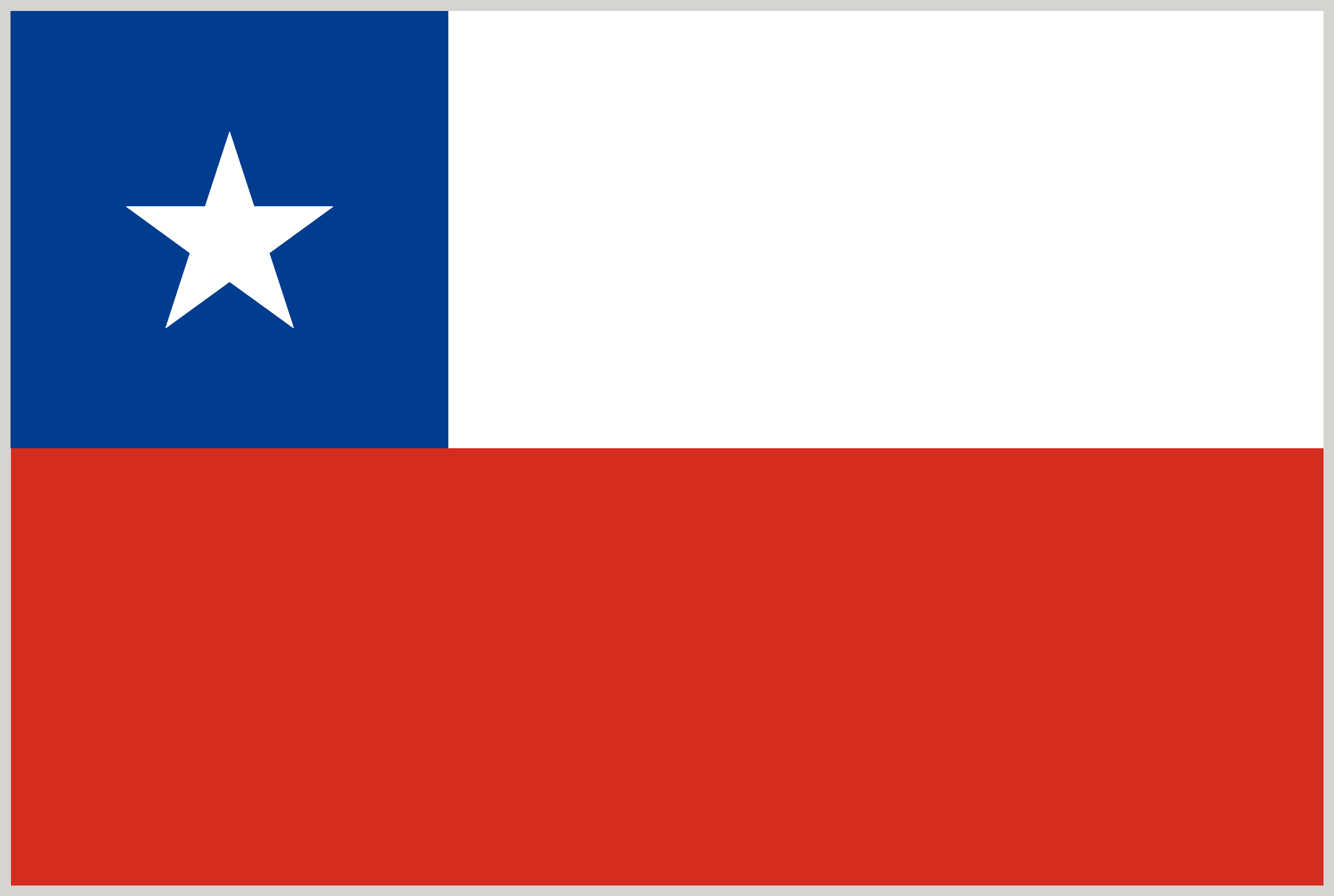

Table 6. Number of times a topic was prioritised in Chile compared with the generic list

	Generic List	Chili			
		Overall	PWD	Carer	Professional
Diet or appetite changes of PWD and/or CP	89	4	0	4	0
Sleep disturbances for PWD and/or CP	142	10	2	7	1
Worsening physical health of PWD and/or CP	151	14	0	14	0
Faster cognitive decline of PWD	197	16	2	13	1
Increased use/dose of medications by PWD	47	3	0	3	0
PWD has difficulty understanding the COVID-19 situation	113	12	0	11	1
CP have difficulty managing COVID-19 control measures in context of PWD not understanding the situation	85	5	0	5	0
Increased anxiety/stress of PWD and/or care partners	182	11	1	10	0
PWD and/or CP feeling hopeless (e.g., feeling discouraged, loss of purpose, feeling the pandemic will never end)	74	3	1	2	0
Mood changes of PWD and/or CP (e.g., increased depression, sadness, mood swings)	139	13	2	11	0
Experiencing grief (PWD and/or CP)	55	1	0	1	0
Concerns about health of PWD	98	12	1	10	1
Concerns about health of CP	51	8	0	8	0
PWD and/or CP concerns about health of family and friends	12	3	1	2	0
CP fears of struggling to cope due to COVID-19 measures	34	2	0	1	1
PWD and/or CP concerns about the future	46	8	1	7	0
Increased behavioural problems of PWD	111	7	1	6	0
Increased social isolation of PWD and/or CP	171	8	0	6	2
Changes in quality of life and/or life satisfaction of PWD and/or CP	83	7	0	7	0
Increased care burden and/or responsibilities of CP	119	10	0	8	2
Positive/negative coping strategies used by PWD and/or CP	32	5	0	5	0
Changes in the quality of relationships for PWD and/or CP	47	3	0	3	0
Changes in social contacts of PWD and/or CP	58	4	0	4	0
Increased stigma experienced by CP during COVID-19 pandemic	7	0	0	0	0
Loss of work/change in work of CP due to COVID-19 measures	34	5	0	5	0
Interruption of physical and/or social activities of PWD and/or CP	57	6	0	6	0
PWD having reduced personal care	39	1	1	0	0
Increased time CP spend caring for person with dementia	46	4	0	4	0
Financial uncertainties/difficulties for PWD and/or CP	53	4	0	4	0
CP experiencing guilt over not being able to visit PWD	22	0	0	0	0
Difficulty in accessing basic needs (e.g., shopping, accessing care)	51	4	0	3	1
Discontinuation/shut down of services (e.g., appointments, doctor visits)	74	3	0	1	2
Lack of access to medical support	68	0	0	0	0
Increased cost of care	34	3	0	3	0
Reduced support for PWD and/or CP	62	4	0	4	0
Increased inequities that existed before COVID-19	20	0	0	0	0
PWD and/or CP avoiding seeking help for health issues out of fear of getting COVID-19 in hospitals or doctor surgeries	65	2	0	1	1
Lack of information on what supports and services were available for PWD and/or CP during the COVID-19 pandemic	64	3	0	3	0

CP Care partner; PWD person with dementia
Highlighted in yellow are the topics with the most votes within that stakeholder group

D.3 COLOMBIA

In Colombia, the Spanish version of the survey was distributed through social media channels and networks. Only 6 care professionals responded to the survey and no persons with dementia or care partners. The Colombian sample of care professionals who responded to the survey were mainly women (83.33%).

Eight of the top ten priorities overlapped with the generic list. Two additional topics that were prioritised, were concerns about the future and lack of access to medical support. Concerns about the future were also prioritised by people with dementia across all participating countries. Given the large overlap between in priorities with the generic list, we believe that the research agenda identified above is adequate for Colombia for care professionals, but a limitation is that it lacks the views of people with the lived experience.

Table 7. Number of times a topic was prioritised in Colombia compared with the generic list

	Generic List	Colombia
		Professional
Diet or appetite changes of PWD and/or CP	89	1
Sleep disturbances for PWD and/or CP	142	6
Worsening physical health of PWD and/or CP	151	3
Faster cognitive decline of PWD	197	9
Increased use/dose of medications by PWD	47	2
PWD has difficulty understanding the COVID-19 situation	113	3
CP have difficulty managing COVID-19 control measures in context of PWD not understanding the situation	85	1
Increased anxiety/stress of PWD and/or care partners	182	4
PWD and/or CP feeling hopeless (e.g., feeling discouraged, loss of purpose, feeling the pandemic will never end)	74	0
Mood changes of PWD and/or CP (e.g., increased depression, sadness, mood swings)	139	3
Experiencing grief (PWD and/or CP)	55	2
Concerns about health of PWD	98	1
Concerns about health of CP	51	0
PWD and/or CP concerns about health of family and friends	12	0
CP fears of struggling to cope due to COVID-19 measures	34	2
PWD and/or CP concerns about the future	46	3
Increased behavioural problems of PWD	111	0
Increased social isolation of PWD and/or CP	171	5
Changes in quality of life and/or life satisfaction of PWD and/or CP	83	2
Increased care burden and/or responsibilities of CP	119	4
Positive/negative coping strategies used by PWD and/or CP	32	1
Changes in the quality of relationships for PWD and/or CP	47	0
Changes in social contacts of PWD and/or CP	58	1
Increased stigma experienced by CP during COVID-19 pandemic	7	1
Loss of work/change in work of CP due to COVID-19 measures	34	1
Interruption of physical and/or social activities of PWD and/or CP	57	2
PWD having reduced personal care	39	0
Increased time CP spend caring for person with dementia	46	1
Financial uncertainties/difficulties for PWD and/or CP	53	1
CP experiencing guilt over not being able to visit PWD	22	0
Difficulty in accessing basic needs (e.g., shopping, accessing care)	51	2
Discontinuation/shut down of services (e.g., appointments, doctor visits)	74	1
Lack of access to medical support	68	3
Increased cost of care	34	2
Reduced support for PWD and/or CP	62	1
Increased inequities that existed before COVID-19	20	1
PWD and/or CP avoiding seeking help for health issues out of fear of getting COVID-19 in hospitals or doctor surgeries	65	1
Lack of information on what supports and services were available for PWD and/or CP during the COVID-19 pandemic	64	1

CP Care partner; PWD person with dementia
Highlighted in yellow are the topics with the most votes within that stakeholder group

D.4 ECUADOR

In Ecuador, the survey was considered a consultancy process and did not require approval from the ethics committee. The Spanish language version of the survey was distributed through informal channels, the Ecuadorian Geriatrics Society social media, caregivers informal groups, and students from the caregivers training program from Pontificia Universidad Católica del Ecuador.

In total 25 participants responded to the survey, 21 health professionals and 4 caregivers. No people living with dementia answered the survey. 100% of care partners were <45 years old, 3 females and 1 man. Showing that women are responsible for caring for older adults more than men. Only one care partner knew the person's diagnosis and the other three did not know the type of dementia of the person they were caring for. That could show the lack of awareness about types of dementia in Ecuador. Health professionals were mostly female (66.6%), which is reflective of the predominantly female professionals in charge of providing medical care to older adults.

Ecuadorian professionals and caregivers identified diet or appetite changes, sleep disturbances, worsening physical health, faster cognitive decline, increased anxiety/stress, and increased social isolation as the main problems they faced during the COVID pandemic.

Table 8. Number of times a topic was prioritised in Ecuador compared with the generic list

	Generic List	Ecuador		
		Overall	Carer	Professional
Diet or appetite changes of PWD and/or CP	89	15	3	12
Sleep disturbances for PWD and/or CP	142	23	4	18
Worsening physical health of PWD and/or CP	151	21	5	15
Faster cognitive decline of PWD	197	12	2	9
Increased use/dose of medications by PWD	47	9	0	6
PWD has difficulty understanding the COVID-19 situation	113	15	2	13
CP have difficulty managing COVID-19 control measures in context of PWD not understanding the situation	85	11	2	8
Increased anxiety/stress of PWD and/or care partners	182	27	4	22
PWD and/or CP feeling hopeless (e.g., feeling discouraged, loss of purpose, feeling the pandemic will never end)	74	13	1	11
Mood changes of PWD and/or CP (e.g., increased depression, sadness, mood swings)	139	18	2	13
Experiencing grief (PWD and/or CP)	55	13	1	12
Concerns about health of PWD	98	8	1	7
Concerns about health of CP	51	5	0	5
PWD and/or CP concerns about health of family and friends	12	6	2	4
CP fears of struggling to cope due to COVID-19 measures	34	3	1	2
PWD and/or CP concerns about the future	46	4	1	3
Increased behavioural problems of PWD	111	8	0	7
Increased social isolation of PWD and/or CP	171	16	4	12
Changes in quality of life and/or life satisfaction of PWD and/or CP	83	9	0	7
Increased care burden and/or responsibilities of CP	119	9	1	7
Positive/negative coping strategies used by PWD and/or CP	32	5	0	4
Changes in the quality of relationships for PWD and/or CP	47	3	0	3
Changes in social contacts of PWD and/or CP	58	2	0	2
Increased stigma experienced by CP during COVID-19 pandemic	7	1	0	1
Loss of work/change in work of CP due to COVID-19 measures	34	6	2	3
Interruption of physical and/or social activities of PWD and/or CP	57	3	1	2
PWD having reduced personal care	39	3	1	2
Increased time CP spend caring for person with dementia	46	2	1	1
Financial uncertainties/difficulties for PWD and/or CP	53	2	2	0
CP experiencing guilt over not being able to visit PWD	22	0	0	0
Difficulty in accessing basic needs (e.g., shopping, accessing care)	51	6	1	5
Discontinuation/shut down of services (e.g., appointments, doctor visits)	74	2	1	1
Lack of access to medical support	68	10	0	8
Increased cost of care	34	11	4	7
Reduced support for PWD and/or CP	62	7	0	6
Increased inequities that existed before COVID-19	20	4	0	4
PWD and/or CP avoiding seeking help for health issues out of fear of getting COVID-19 in hospitals or doctor surgeries	65	6	0	4
Lack of information on what supports and services were available for PWD and/or CP during the COVID-19 pandemic	64	8	2	5

CP Care partner; PWD person with dementia
Highlighted in yellow are the topics with the most votes within that stakeholder group

D.5 FRANCE

In France, the survey was considered as a consultancy process for professional and care partners. The survey was declared to the DPO of University Hospital of Lille, and registered nationally under the number DEC23-157. However, it was not possible to solicit patients with dementia without ethics committee approval. The request timeframe was not compatible with this research project. The survey was distributed through the network of geriatricians and neurologists who work in memory clinics, and different platforms for carers, especially the national respite platform for carers.

In total 9 participants responded to the survey, 6 health professionals and 3 care partners. Although the number of participants was small, the carers who answered the survey were aged above 65 years old, which was higher than from the demographic profile of the overall respondents. This leads to an interesting interpretation for older carers, who may face different challenges than younger carers.

Increased loneliness for patients and carers was considered as the research priority by both professional and lay carers. The mental health, especially increased anxiety, was also considered a major research priority. As the second most important topic, the health professionals called for more research on faster cognitive decline and increased behavioral disorders for patients with dementia, whereas the care partners considered research on quality of life the second most important topic.

Overall, answers from France align with the findings in the whole group and generic research agenda.

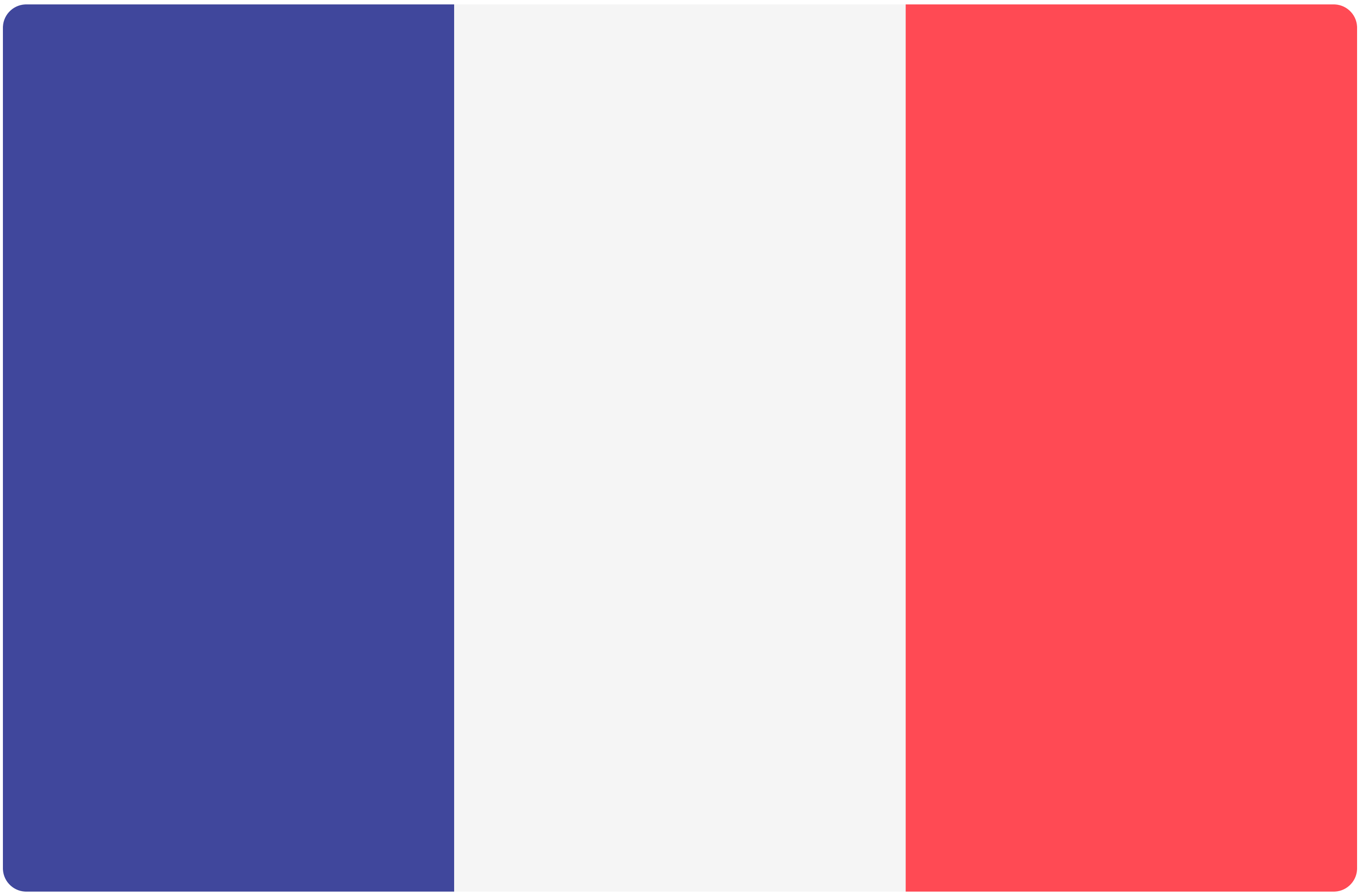

Table 9. Number of times a topic was prioritised in France compared with the generic list

	Generic List	France		
		Overall	Carer	Professional
Diet or appetite changes of PWD and/or CP	89	1	1	0
Sleep disturbances for PWD and/or CP	142	2	1	1
Worsening physical health of PWD and/or CP	151	1	1	0
Faster cognitive decline of PWD	197	7	2	5
Increased use/dose of medications by PWD	47	2	0	2
PWD has difficulty understanding the COVID-19 situation	113	3	1	2
CP have difficulty managing COVID-19 control measures in context of PWD not understanding the situation	85	1	0	1
Increased anxiety/stress of PWD and/or care partners	182	7	2	5
PWD and/or CP feeling hopeless (e.g., feeling discouraged, loss of purpose, feeling the pandemic will never end)	74	1	0	1
Mood changes of PWD and/or CP (e.g., increased depression, sadness, mood swings)	139	2	2	0
Experiencing grief (PWD and/or CP)	55	4	0	4
Concerns about health of PWD	98	0	0	0
Concerns about health of CP	51	0	0	0
PWD and/or CP concerns about health of family and friends	12	0	0	0
CP fears of struggling to cope due to COVID-19 measures	34	1	0	1
PWD and/or CP concerns about the future	46	1	1	0
Increased behavioural problems of PWD	111	6	0	6
Increased social isolation of PWD and/or CP	171	12	6	6
Changes in quality of life and/or life satisfaction of PWD and/or CP	83	5	3	2
Increased care burden and/or responsibilities of CP	119	2	1	1
Positive/negative coping strategies used by PWD and/or CP	32	1	0	1
Changes in the quality of relationships for PWD and/or CP	47	1	1	0
Changes in social contacts of PWD and/or CP	58	2	2	0
Increased stigma experienced by CP during COVID-19 pandemic	7	0	0	0
Loss of work/change in work of CP due to COVID-19 measures	34	0	0	0
Interruption of physical and/or social activities of PWD and/or CP	57	5	3	2
PWD having reduced personal care	39	2	2	0
Increased time CP spend caring for person with dementia	46	7	3	4
Financial uncertainties/difficulties for PWD and/or CP	53	0	0	0
CP experiencing guilt over not being able to visit PWD	22	1	0	1
Difficulty accessing basic needs (e.g. shopping, accessing care)	51	1	0	1
Discontinuation/shut down of services (e.g. doctor visits)	74	4	0	4
Lack of access to medical support	68	2	0	2
Increased cost of care	34	0	0	0
Reduced support for PWD and/or CP	62	4	2	2
Increased inequities that existed before COVID-19	20	1	0	1
PWD and/or CP avoiding seeking help for health issues out of fear of getting COVID-19 in hospitals or doctor surgeries	65	1	0	1
Lack of information on what supports and services were available for PWD and/or CP during the COVID-19 pandemic	64	1	1	0

CP Care partner; PWD person with dementia
Highlighted in yellow are the topics with the most votes within that stakeholder group

D.6 GREECE

In Greece, the survey was considered research and the protocol was approved by the Alzheimer Hellas ethics review board in Greece. The survey was distributed through formal and informal networks, organisations and institutions that support, research and engage with people living with dementia, carers and professionals. In total, 25 responses were received. No people with dementia responded, as they had no opportunity in the past to use new technologies. 15 care partners and 10 care professionals responded. We believe that the research agenda identified above is adequate for Greece for care partners and care professionals, but a limitation is that it lacks the views of people with dementia.

Table 10. Number of times a topic was prioritised in Greece compared with the generic list

	Generic List	Greece		
		Overall	Carer	Professional
Diet or appetite changes of PWD and/or CP	89	1	1	0
Sleep disturbances for PWD and/or CP	142	6	4	2
Worsening physical health of PWD and/or CP	151	13	7	6
Faster cognitive decline of PWD	197	15	6	9
Increased use/dose of medications by PWD	47	3	1	2
PWD has difficulty understanding the COVID-19 situation	113	11	9	2
CP have difficulty managing COVID-19 control measures in context of PWD not understanding the situation	85	14	11	3
Increased anxiety/stress of PWD and/or care partners	182	21	10	11
PWD and/or CP feeling hopeless (e.g., feeling discouraged, loss of purpose, feeling the pandemic will never end)	74	3	1	2
Mood changes of PWD and/or CP (e.g., increased depression, sadness, mood swings)	139	16	7	9
Experiencing grief (PWD and/or CP)	55	4	2	2
Concerns about health of PWD	98	16	11	5
Concerns about health of CP	51	7	6	1
PWD and/or CP concerns about health of family and friends	12	3	2	1
CP fears of struggling to cope due to COVID-19 measures	34	2	1	1
PWD and/or CP concerns about the future	46	3	2	1
Increased behavioural problems of PWD	111	9	4	5
Increased social isolation of PWD and/or CP	171	19	8	11
Changes in quality of life and/or life satisfaction of PWD and/or CP	83	14	10	4
Increased care burden and/or responsibilities of CP	119	13	8	5
Positive/negative coping strategies used by PWD and/or CP	32	3	1	2
Changes in the quality of relationships for PWD and/or CP	47	1	1	0
Changes in social contacts of PWD and/or CP	58	6	5	1
Increased stigma experienced by CP during COVID-19 pandemic	7	0	0	0
Loss of work/change in work of CP due to COVID-19 measures	34	3	3	0
Interruption of physical and/or social activities of PWD and/or CP	57	19	10	9
PWD having reduced personal care	39	3	3	0
Increased time CP spend caring for person with dementia	46	5	2	3
Financial uncertainties/difficulties for PWD and/or CP	53	6	5	1
CP experiencing guilt over not being able to visit PWD	22	5	0	5
Difficulty in accessing basic needs (e.g., shopping, accessing care)	51	4	2	2
Discontinuation/shut down of services (e.g., appointments, doctor visits)	74	8	5	3
Lack of access to medical support	68	12	7	5
Increased cost of care	34	5	5	0
Reduced support for PWD and/or CP	62	8	3	5
Increased inequities that existed before COVID-19	20	1	1	0
PWD and/or CP avoiding seeking help for health issues out of fear of getting COVID-19 in hospitals or doctor surgeries	65	4	2	2
Lack of information on what supports and services were available for PWD and/or CP during the COVID-19 pandemic	64	4	2	2

CP Care partner; PWD person with dementia
Highlighted in yellow are the topics with the most votes within that stakeholder group

D.6 INDIA

In India, the survey was approved by the Institutional Ethics Committee of the National Institute of Mental Health and Neurosciences (NIMHANS). It was disseminated to health care professionals and administered on the care partners of people with dementia attending the outpatient department of the Cognitive Disorders Clinic of the National Institute of Mental Health and Neurosciences. 3 health professionals responded to the survey and the feedback was recorded from 9 care partners. No people living with dementia could be enrolled in this survey.

Majority of the care partners were under 45 years of age and indicated having a somewhat difficult experience in managing income. This lends a viewpoint on the interpretation of the challenges faced by the young carers. Six of the top ten priorities cited on the generic list also gathered the most votes from the Indian respondents. Topics that were prioritised in India, but not included in the generic list were CP fears of struggling to cope due to COVID-19 measures, changes in quality of life of PWD and/or CP, changes in social contacts of PWD and/or CP, loss of work/change in work of CP due to COVID-19 measures, financial uncertainties/difficulties for PWD and/or CP, and lack of information on what supports and services were available for PWD and/or CP during the COVID-19 pandemic. These were only differently prioritised by the care partners and were not raised as a concern by the health care professionals. These concerns can be understood considering that India is a lower-middle income country and the containment and lockdown measures had a severely detrimental effect on livelihood and food security, provoking economic vulnerability. In conclusion, the generic research agenda is also relevant for India, but with the addition that the economic situation of care partners should be taken into account in future research as well as resulting policy recommendations.

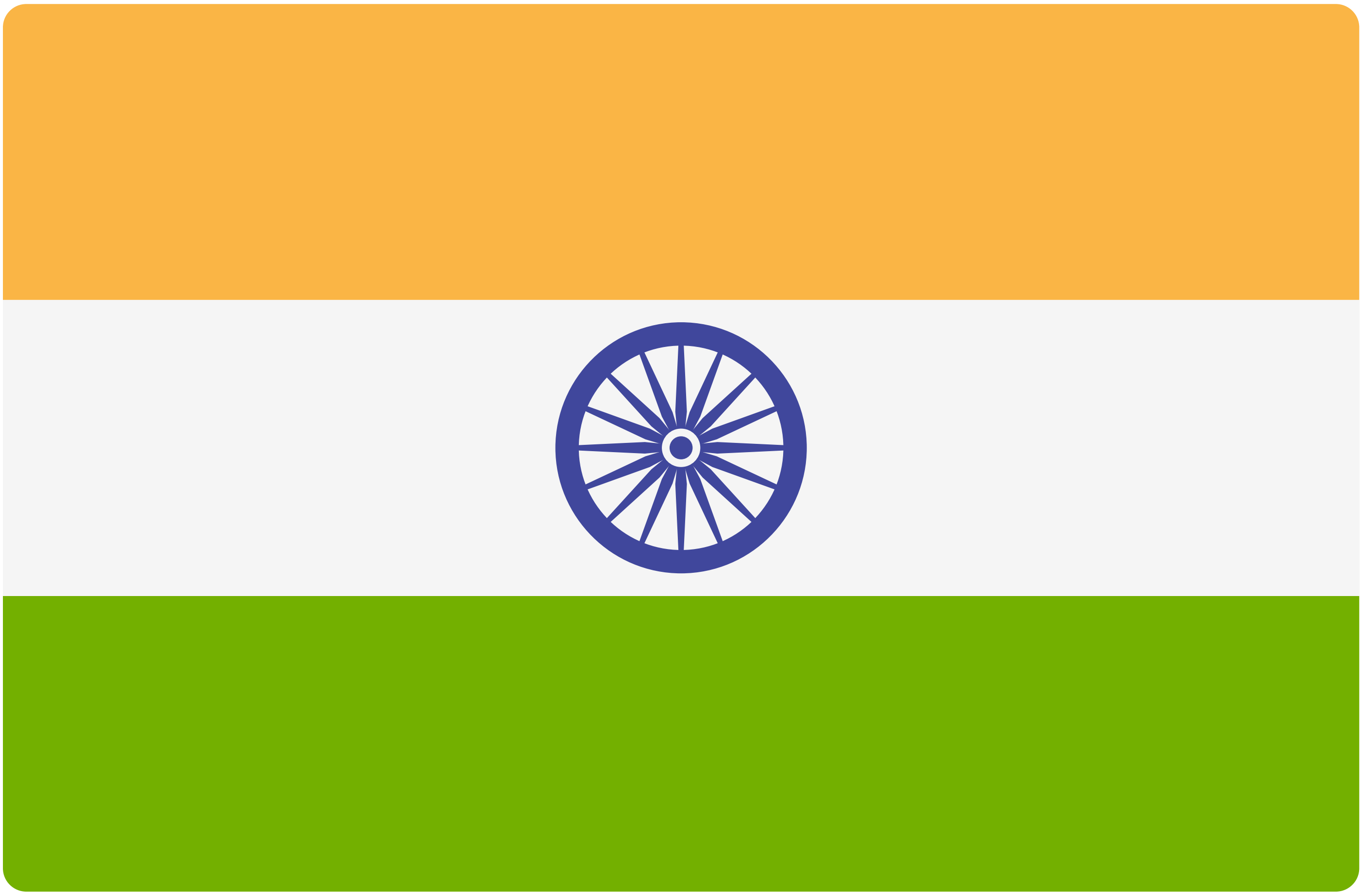

Table 11. Number of times a topic was prioritised in India compared with the generic list

	Generic List	Ireland			
		Overall	PWD	Carer	Professional
Diet or appetite changes of PWD and/or CP	89	2	2	0	2
Sleep disturbances for PWD and/or CP	142	2	1	1	2
Worsening physical health of PWD and/or CP	151	2	2	0	1
Faster cognitive decline of PWD	197	8	8	0	6
Increased use/dose of medications by PWD	47	1	0	1	2
PWD has difficulty understanding the COVID-19 situation	113	2	1	1	1
CP have difficulty managing COVID-19 control measures in context of PWD not understanding the situation	85	3	2	1	1
Increased anxiety/stress of PWD and/or care partners	182	4	4	0	1
PWD and/or CP feeling hopeless (e.g., feeling discouraged, loss of purpose, feeling the pandemic will never end)	74	2	1	1	3
Mood changes of PWD and/or CP (e.g., increased depression, sadness, mood swings)	139	4	4	0	4
Experiencing grief (PWD and/or CP)	55	0	0	0	2
Concerns about health of PWD	98	6	6	0	1
Concerns about health of CP	51	1	1	0	0
PWD and/or CP concerns about health of family and friends	12	0	0	0	1
CP fears of struggling to cope due to COVID-19 measures	34	4	4	0	0
PWD and/or CP concerns about the future	46	2	2	0	1
Increased behavioural problems of PWD	111	7	5	2	6
Increased social isolation of PWD and/or CP	171	6	4	2	7
Changes in quality of life and/or life satisfaction of PWD and/or CP	83	4	4	0	3
Increased care burden and/or responsibilities of CP	119	3	2	1	1
Positive/negative coping strategies used by PWD and/or CP	32	3	2	1	0
Changes in the quality of relationships for PWD and/or CP	47	1	1	0	2
Changes in social contacts of PWD and/or CP	58	5	4	1	1
Increased stigma experienced by CP during COVID-19 pandemic	7	0	0	0	0
Loss of work/change in work of CP due to COVID-19 measures	34	4	3	1	0
Interruption of physical and/or social activities of PWD and/or CP	57	0	0	0	7
PWD having reduced personal care	39	0	0	0	0
Increased time CP spend caring for person with dementia	46		3	1	0
Financial uncertainties/difficulties for PWD and/or CP	53	4	4	0	1
CP experiencing guilt over not being able to visit PWD	22	0	0	0	1
Difficulty accessing basic needs (e.g. shopping, accessing care)	51	1	0	1	3
Discontinuation/shut down of services (e.g. doctor visits)	74	2	1	1	6
Lack of access to medical support	68	0	0	0	6
Increased cost of care	34	0	0	0	1
Reduced support for PWD and/or CP	62	0	0	0	4
Increased inequities that existed before COVID-19	20	0	0	0	0
PWD and/or CP avoiding seeking help for health issues out of fear of getting COVID-19 in hospitals or doctor surgeries	65	1	0	1	6
Lack of information on what supports and services were available for PWD and/or CP during the COVID-19 pandemic	64	4	3	1	1

CP Care partner; PWD person with dementia

Highlighted in yellow are the topics with the most votes within that stakeholder group

D.8 IRELAND

In Ireland, the English version survey received ethical approval from the Research Ethics Committee of the Centre for Health Policy and Management at Trinity College Dublin (reference number 2023). The survey was disseminated through social media channels, PPI networks, and mailing lists of Trinity College Dublin. In total, 4 people with dementia, 9 care partners, and 7 health professionals responded to the survey. Most participants (65%) identified as female. Diagnoses included Alzheimer’s disease, Vascular dementia, Lewy body disease, and frontotemporal dementia. Nearly half of respondents (45%) rated their financial situation as difficult. Table X shows that there was substantial overlap between the top priorities identified by respondents in Ireland and the generic list. These included cognitive and mood changes, sleep disturbances, behavioural problems, social isolation, and increased care burden. When the groups were examined separately, sleep disturbances were prioritised by people with dementia and carers, but not by health care professionals. Mood changes were prioritised by carers and health care professionals. Increased care burden was prioritised by carers only. Topics prioritised in Ireland that were not included in the generic list were: changes in quality of life and relationships, interruption of physical or social activities, lack of medical support, avoidance of help seeking due to fear of COVID-19, and lack of information about available supports during the pandemic.

Avoidance of help seeking was prioritised by people with dementia and health care professionals. Both groups also prioritised behavioural problems. Changes in quality of life and interruptions in activities were prioritised by carers and health care professionals. Changes in relationships were prioritised by people with dementia only, who also highlighted future concerns. Lack of medical support was prioritised by health care professionals only. Relatedly, health care professionals also prioritized service closures and reduced supports, as well as difficulty accessing basic needs and feelings of hopelessness. Lack of information about COVID-19 was prioritised by carers, who also highlighted issues around difficulties understanding the COVID-19 situation by the person with dementia. People with dementia and carers prioritised changes in physical health and increased anxiety.

The priorities for Ireland align well with the pillars of the research agenda (Figure 4), particularly ‘physical health and routine’, which includes disrupted activities, and ‘carer impact’. Carer impact, which includes burden and difficulty managing, aligns with the lack of medical support and information, and avoidance of help seeking. Finally, the ‘mental health’ pillar, which includes social isolation, aligns with the prioritisation of changes in relationships. Based on these findings, we believe that the priorities identified in Ireland are adequately represented by the research agenda.

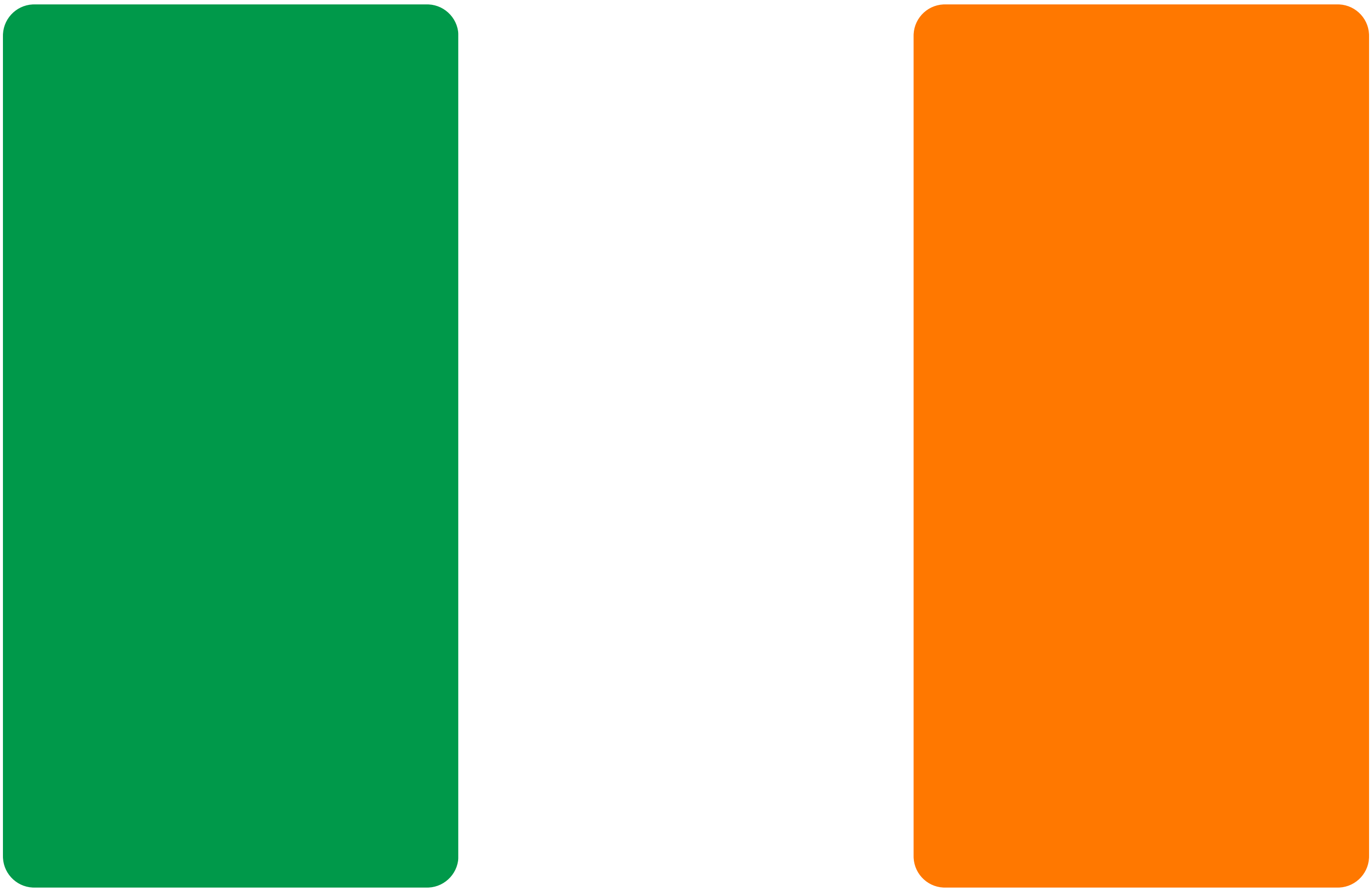

Table 12. Number of times a topic was prioritised in Ireland compared with the generic list

	Generic List	Ireland			
		Overall	PWD	Carer	Professional
Diet or appetite changes of PWD and/or CP	89	5	0	3	2
Sleep disturbances for PWD and/or CP	142	12	3	7	2
Worsening physical health of PWD and/or CP	151	8	3	4	1
Faster cognitive decline of PWD	197	17	4	7	6
Increased use/dose of medications by PWD	47	5	2	1	2
PWD has difficulty understanding the COVID-19 situation	113	7	0	6	1
CP have difficulty managing COVID-19 control measures in context of PWD not understanding the situation	85	4	1	2	1
Increased anxiety/stress of PWD and/or care partners	182	8	3	4	1
PWD and/or CP feeling hopeless (e.g., feeling discouraged, loss of purpose, feeling the pandemic will never end)	74	8	2	3	3
Mood changes of PWD and/or CP (e.g., increased depression, sadness, mood swings)	139	13	1	8	4
Experiencing grief (PWD and/or CP)	55	4	2	0	2
Concerns about health of PWD	98	2	1	0	1
Concerns about health of CP	51	0	0	0	0
PWD and/or CP concerns about health of family and friends	12	3	0	2	1
CP fears of struggling to cope due to COVID-19 measures	34	4	1	3	0
PWD and/or CP concerns about the future	46	5	3	1	1
Increased behavioural problems of PWD	111	12	4	2	6
Increased social isolation of PWD and/or CP	171	16	3	6	7
Changes in quality of life and/or life satisfaction of PWD and/or CP	83	12	2	7	3
Increased care burden and/or responsibilities of CP	119	9	1	7	1
Positive/negative coping strategies used by PWD and/or CP	32	1	0	1	0
Changes in the quality of relationships for PWD and/or CP	47	9	4	3	2
Changes in social contacts of PWD and/or CP	58	2	0	1	1
Increased stigma experienced by CP during COVID-19 pandemic	7	0	0	0	0
Loss of work/change in work of CP due to COVID-19 measures	34	3	1	2	0
Interruption of physical and/or social activities of PWD and/or CP	57	14	2	5	7
PWD having reduced personal care	39	1	1	0	0
Increased time CP spend caring for person with dementia	46	0	0	0	0
Financial uncertainties/difficulties for PWD and/or CP	53	2	0	1	1
CP experiencing guilt over not being able to visit PWD	22	3	0	2	1
Difficulty accessing basic needs (e.g., shopping, accessing care)	51	6	1	2	3
Discontinuation/shut down of services (e.g. doctor visits)	74	8	0	2	6
Lack of access to medical support	68	9	2	1	6
Increased cost of care	34	1	0	0	1
Reduced support for PWD and/or CP	62	6	0	2	4
Increased inequities that existed before COVID-19	20	0	0	0	0
PWD and/or CP avoiding seeking help for health issues out of fear of getting COVID-19 in hospitals or doctor surgeries	65	12	4		6
Lack of information on what supports and services were available for PWD and/or CP during the COVID-19 pandemic	64	10	1	8	1

CP Care partner; PWD person with dementia

Highlighted in yellow are the topics with the most votes within that stakeholder group

D.9 NEPAL

In Nepal, the survey was considered a consultative process rather than research, and therefore did not require approval from an ethics review committee. The English STRAP survey was translated into Nepali, and necessary modifications were made based on reviewer feedback. We consulted people living with dementia and their care partners attending the geriatric outpatient department of B.P. Koirala Institute of Health Sciences (BPKIHS). We administered both online and paper surveys based on the needs and preferences of the participants. A total of 10 participants were enrolled in the survey, including 2 care partners, 6 health professionals, and 2 social workers working in care homes. We could not enroll people living with dementia in this survey, as those visiting the out-patient department of BPKIHS were at the later stage of dementia and were not capable of participating in the survey.

Table 13 shows that the priorities of the Nepalese participants overlapped largely with the generic list. Hence, the research agenda also applies to the situation in Nepal, with perhaps extra attention for access to personal and medical care.

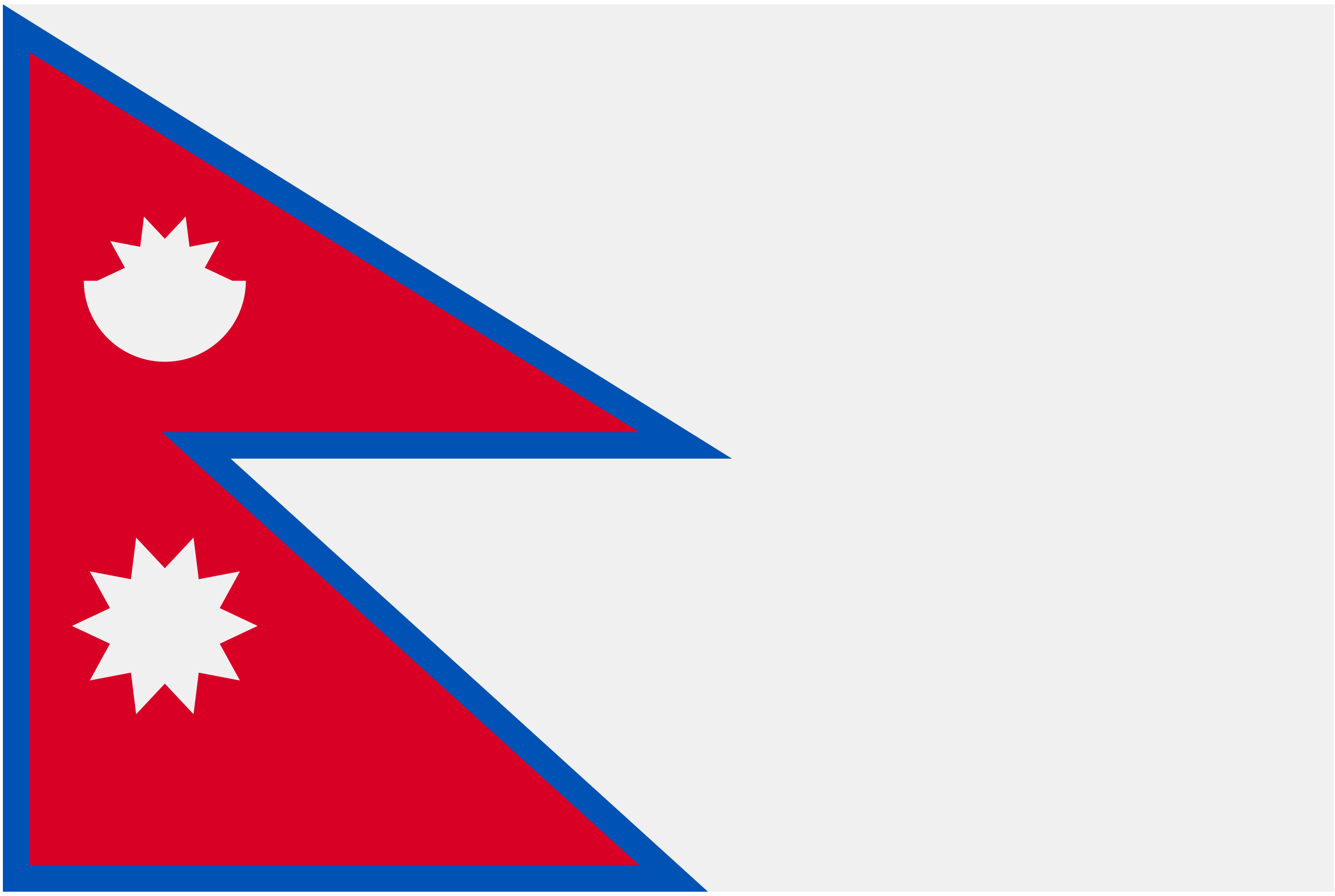

Table 13. Number of times a topic was prioritised in Nepal compared with the generic list

	Generic List	Nepal		
		Overall	Carer	Professional
Diet or appetite changes of PWD and/or CP	89	10	1	9
Sleep disturbances for PWD and/or CP	142	9	6	3
Worsening physical health of PWD and/or CP	151	6	2	4
Faster cognitive decline of PWD	197	3	3	0
Increased use/dose of medications by PWD	47	1	1	0
PWD has difficulty understanding the COVID-19 situation	113	2	1	1
CP have difficulty managing COVID-19 control measures in context of PWD not understanding the situation	85	4	0	4
Increased anxiety/stress of PWD and/or care partners	182	12	4	8
PWD and/or CP feeling hopeless (e.g., feeling discouraged, loss of purpose, feeling the pandemic will never end)	74	4	0	4
Mood changes of PWD and/or CP (e.g., increased depression, sadness, mood swings)	139	6	1	5
Experiencing grief (PWD and/or CP)	55	4	0	4
Concerns about health of PWD	98	3	1	2
Concerns about health of CP	51	5	1	4
PWD and/or CP concerns about health of family and friends	12	0	0	0
CP fears of struggling to cope due to COVID-19 measures	34	1	1	0
PWD and/or CP concerns about the future	46	7	1	6
Increased behavioural problems of PWD	111	3	2	1
Increased social isolation of PWD and/or CP	171	2	0	2
Changes in quality of life and/or life satisfaction of PWD and/or CP	83	3	1	2
Increased care burden and/or responsibilities of CP	119	6	4	2
Positive/negative coping strategies used by PWD and/or CP	32	2	0	2
Changes in the quality of relationships for PWD and/or CP	47	5	2	3
Changes in social contacts of PWD and/or CP	58	5	2	3
Increased stigma experienced by CP during COVID-19 pandemic	7	2	0	2
Loss of work/change in work of CP due to COVID-19 measures	34	2	1	1
Interruption of physical and/or social activities of PWD and/or CP	57	0	0	0
PWD having reduced personal care	39	8	2	6
Increased time CP spend caring for person with dementia	46	0	0	0
Financial uncertainties/difficulties for PWD and/or CP	53	3	0	3
CP experiencing guilt over not being able to visit PWD	22	2	0	2
Difficulty accessing basic needs (e.g., shopping, accessing care)	51	2	0	2
Discontinuation/shut down of services (e.g. doctor visits)	74	5	3	2
Lack of access to medical support	68	8	2	6
Increased cost of care	34	3	1	2
Reduced support for PWD and/or CP	62	2	1	1
Increased inequities that existed before COVID-19	20	0	0	0
PWD and/or CP avoiding seeking help for health issues out of fear of getting COVID-19 in hospitals or doctor surgeries	65	3	0	3
Lack of information on what supports and services were available for PWD and/or CP during the COVID-19 pandemic	64	4	1	3

CP Care partner; PWD person with dementia

Highlighted in yellow are the topics with the most votes within that stakeholder group

D.10 NETHERLANDS

In the Netherlands, the survey was considered a consultancy process and therefore did not require approval from an ethics review board. The Dutch language version of the survey was distributed through social media channels and mailing lists of the Radboudumc Alzheimer Centre in Nijmegen. Although all three stakeholder groups were invited to participate, no people with dementia responded to the survey. However, some care partners indicated that they responded to the survey together with the person they care for. In total, 7 care partners and 10 care professionals responded to the survey.

Table 2 shows that there is substantial overlap between the topics that received the most votes from the Dutch respondents and the generic list. Topics that were prioritised in the Netherlands, but not in the generic list, included ‘changes in social contacts’ and ‘reduced support’. The topic ‘changes in social contacts’ aligns with the topic ‘increased social isolation’, which is included in the research agenda. It is interesting to see that ‘reduced support’ was prioritised by care professionals, but not by care partners, suggesting that care partners did not seem to experience this as an issue. However, reduced support may lead to an increase in care burden, which was prioritised by the care partners. Given the alignment of priorities in the Netherlands with the generic list, we believe that the research agenda (Figure 4) is adequate for the Netherlands.

Table 14. Number of times a topic was prioritised in the Netherlands compared with the generic list

	Generic List	Nederland	
		Carer	Professional
Diet or appetite changes of PWD and/or CP	89	4	0
Sleep disturbances for PWD and/or CP	142	1	0
Worsening physical health of PWD and/or CP	151	2	6
Faster cognitive decline of PWD	197	8	12
Increased use/dose of medications by PWD	47	0	1
PWD has difficulty understanding the COVID-19 situation	113	4	5
CP have difficulty managing COVID-19 control measures in context of PWD not understanding the situation	85	4	5
Increased anxiety/stress of PWD and/or care partners	182	1	0
PWD and/or CP feeling hopeless (e.g., feeling discouraged, loss of purpose, feeling the pandemic will never end)	74	2	1
Mood changes of PWD and/or CP (e.g., increased depression, sadness, mood swings)	139	5	3
Experiencing grief (PWD and/or CP)	55	0	3
Concerns about health of PWD	98	4	2
Concerns about health of CP	51	2	0
PWD and/or CP concerns about health of family and friends	12	2	1
CP fears of struggling to cope due to COVID-19 measures	34	1	1
PWD and/or CP concerns about the future	46	1	1
Increased behavioural problems of PWD	111	1	2
Increased social isolation of PWD and/or CP	171	9	11
Changes in quality of life and/or life satisfaction of PWD and/or CP	83	1	3
Increased care burden and/or responsibilities of CP	119	7	10
Positive/negative coping strategies used by PWD and/or CP	32	0	0
Changes in the quality of relationships for PWD and/or CP	47	1	3
Changes in social contacts of PWD and/or CP	58	5	5
Increased stigma experienced by CP during COVID-19 pandemic	7	0	0
Loss of work/change in work of CP due to COVID-19 measures	34	1	0
Interruption of physical and/or social activities of PWD and/or CP	57	2	6
PWD having reduced personal care	39	3	2
Increased time CP spend caring for person with dementia	46	1	0
Financial uncertainties/difficulties for PWD and/or CP	53	1	0
CP experiencing guilt over not being able to visit PWD	22	2	1
Difficulty accessing basic needs (e.g., shopping, accessing care)	51	0	3
Discontinuation/shut down of services (e.g. doctor visits)	74	3	1
Lack of access to medical support	68	0	2
Increased cost of care	34	0	0
Reduced support for PWD and/or CP	62	1	4
Increased inequities that existed before COVID-19	20	0	1
PWD and/or CP avoiding seeking help for health issues out of fear of getting COVID-19 in hospitals or doctor surgeries	65	0	2
Lack of information on what supports and services were available for PWD and/or CP during the COVID-19 pandemic	64	3	1

CP Care partner; PWD person with dementia

Highlighted in yellow are the topics with the most votes within that stakeholder group

D.11 Nigeria

In Nigeria, the survey was translated into Yoruba, one of the major local languages, and ethical approval was obtained from the UI/UCH ethics committees (reference number UI/EC/23/0530). The survey was disseminated among 24 respondents: 10 healthcare workers, 8 persons with dementia, and 6 care partners attending the Neurology clinic of the Chief Tony Anenih Geriatric Center at the University College Hospital. Among the participants living with dementia, the majority were male (62.5%), with 87.5% having Alzheimer's dementia and 12.5% having vascular dementia. A significant portion (57.1%) reported difficulties managing finances.

Table 15 highlights a notable overlap between the top priorities identified by the Nigerian respondents and the generic list. However, in Nigeria, priorities specific to the context include diet, sleep disturbances, worsening physical health, cognitive decline, anxiety, and mood changes. Financial uncertainty and the discontinuation of services were major concerns for respondents, which were not prioritized in the general list. This is reflective of the fact that health service costs in Nigeria are typically out-of-pocket, and access to quality healthcare services remains a significant challenge for many Nigerians. In summary, the generic research agenda is also relevant for Nigeria, but the economic context should be taken into account in future research and resulting recommendations for policy.

Table 15. Number of times a topic was prioritised in Nigeria compared with the generic list

	Generic List	Nigeria			
		Overall	PWD	Carer	Professional
Diet or appetite changes of PWD and/or CP	89	10	2	2	6
Sleep disturbances for PWD and/or CP	142	14	5	3	6
Worsening physical health of PWD and/or CP	151	16	5	1	10
Faster cognitive decline of PWD	197	14	6	3	5
Increased use/dose of medications by PWD	47	10	2	0	8
PWD has difficulty understanding the COVID-19 situation	113	11	5	1	5
CP have difficulty managing COVID-19 control measures in context of PWD not understanding the situation	85	1	0	0	1
Increased anxiety/stress of PWD and/or care partners	182	21	10	2	9
PWD and/or CP feeling hopeless (e.g., feeling discouraged, loss of purpose, feeling the pandemic will never end)	74	7	2	2	3
Mood changes of PWD and/or CP (e.g., increased depression, sadness, mood swings)	139	11	4	3	4
Experiencing grief (PWD and/or CP)	55	7	2	2	3
Concerns about health of PWD	98	8	1	2	5
Concerns about health of CP	51	7	0	4	3
PWD and/or CP concerns about health of family and friends	12	0	0	0	0
CP fears of struggling to cope due to COVID-19 measures	34	4	0	0	4
PWD and/or CP concerns about the future	46	2	0	0	2
Increased behavioural problems of PWD	111	6	1	4	1
Increased social isolation of PWD and/or CP	171	9	1	3	5
Changes in quality of life and/or life satisfaction of PWD and/or CP	83	3	1	1	1
Increased care burden and/or responsibilities of CP	119	7	0	4	3
Positive/negative coping strategies used by PWD and/or CP	32	3	2	0	1
Changes in the quality of relationships for PWD and/or CP	47	6	0	2	4
Changes in social contacts of PWD and/or CP	58	4	1	3	0
Increased stigma experienced by CP during COVID-19 pandemic	7	1	0	1	0
Loss of work/change in work of CP due to COVID-19 measures	34	2	0	1	1
Interruption of physical and/or social activities of PWD and/or CP	57	0	0	0	0
PWD having reduced personal care	39	4	2	0	2
Increased time CP spend caring for person with dementia	46	5	0	5	0
Financial uncertainties/difficulties for PWD and/or CP	53	16	8	7	1
CP experiencing guilt over not being able to visit PWD	22	0	0	0	0
Difficulty in accessing basic needs (e.g., shopping, accessing care)	51	6	3	1	2
Discontinuation/shut down of services (e.g., appointments, doctor visits)	74	11	2	3	6
Lack of access to medical support	68	9	2	3	4
Increased cost of care	34	3	2	0	1
Reduced support for PWD and/or CP	62	6	2	0	4
Increased inequities that existed before COVID-19	20	1	0	0	1
PWD and/or CP avoiding seeking help for health issues out of fear of getting COVID-19 in hospitals or doctor surgeries	65	10	2	4	4
Lack of information on what supports and services were available for PWD and/or CP during the COVID-19 pandemic	64	4	1	2	1

CP Care partner; PWD person with dementia
Highlighted in yellow are the topics with the most votes within that stakeholder group

D.12 Peru

In Peru, the survey was considered a consultancy process and therefore did not require approval from an ethics review committee. The Spanish version of the survey was distributed to patients and carers attending the Instituto Peruano de Neurociencias in Lima, as well as to dementia related health professionals across the country. Among the 3 main stakeholder groups, an almost equal numbers responded; 7 people with dementia, 7 informal carers and 6 care professionals responded to the survey.

Table 2 shows that there is overlap between the majority of the prioritised topics by respondents in the Peruvian sample and the generic list. However, there are 5 topics that were prioritised in Peru but not included in the generic list,. These were ‘Increased use/dose of medications by PWD’, ‘Informal carers have difficulty managing COVID-19 control measures’, ‘PWD and/or informal carers feeling hopeless’, ‘PWD and/or informal carer concerns about health of family and friends’ and ‘Person with dementia and/or informal carer concerns about the future’. To understand these findings in the Peru vs. generic data, it is important to consider that Peru is a low- and middle-income country, where the pandemic had a severe social and economic impact; furthermore, Peru had the highest number of deaths per 100,000 inhabitants worldwide. These factors could explain why people felt hopeless, concerned about the future, and concerned deeply about their friends’ and family members’ health. The lockdown during the time of COVID-19 in Peru was far longer and stricter than in other countries. The country was paralysed for months, making it very difficult for the care partners, to explain what was happening and why from one day to another people with dementia could not go out for months at a time. This also contributed to many of the patients decompensating and needing to increase the dosage of their medication, as shown in previous research among in people with AD (2). Most patients experienced a new onset or worsening of neuropsychiatric symptoms in addition to further decline in cognition. Considering that the majority of the priorities between Peru and the generic list align and that these five additional topics prioritised in Peru cover similar topics to those that were in the generic list, we believe that the research agenda (Figure 4) is appropriate for this country.

Table 16. Number of times a topic was prioritised in Peru compared with the generic list

	Generic List	Peru			
		Overall	PWD	Carer	Professional
Diet or appetite changes of PWD and/or CP	89	22	11	11	0
Sleep disturbances for PWD and/or CP	142	26	13	10	3
Worsening physical health of PWD and/or CP	151	21	9	7	5
Faster cognitive decline of PWD	197	23	6	9	8
Increased use/dose of medications by PWD	47	8	4	2	2
PWD has difficulty understanding the COVID-19 situation	113	17	6	4	7
CP have difficulty managing COVID-19 control measures in context of PWD not understanding the situation	85	7	1	4	2
Increased anxiety/stress of PWD and/or care partners	182	24	8	9	7
PWD and/or CP feeling hopeless (e.g., feeling discouraged, loss of purpose, feeling the pandemic will never end)	74	11	3	5	3
Mood changes of PWD and/or CP (e.g., increased depression, sadness, mood swings)	139	15	6	5	4
Experiencing grief (PWD and/or CP)	55	4	0	3	1
Concerns about health of PWD	98	9	3	5	1
Concerns about health of CP	51	6	1	3	2
PWD and/or CP concerns about health of family and friends	12	5	4	1	0
CP fears of struggling to cope due to COVID-19 measures	34	1	0	0	1
PWD and/or CP concerns about the future	46	6	6	0	0
Increased behavioural problems of PWD	111	9	2	2	5
Increased social isolation of PWD and/or CP	171	6	2	0	4
Changes in quality of life and/or life satisfaction of PWD and/or CP	83	3	1	1	1
Increased care burden and/or responsibilities of CP	119	6	0	1	5
Positive/negative coping strategies used by PWD and/or CP	32	1	0	1	0
Changes in the quality of relationships for PWD and/or CP	47	0	0	0	0
Changes in social contacts of PWD and/or CP	58	1	0	0	1
Increased stigma experienced by CP during COVID-19 pandemic	7	0	0	0	0
Loss of work/change in work of CP due to COVID-19 measures	34	1	0	0	1
Interruption physical and/or social activities of PWD and/or CP	57	0	0	0	0
PWD having reduced personal care	39	3	0	0	3
Increased time CP spend caring for person with dementia	46	3	1	0	2
Financial uncertainties/difficulties for PWD and/or CP	53	0	0	0	0
CP experiencing guilt over not being able to visit PWD	22	0	0	0	0
Difficulty accessing basic needs (e.g. shopping, accessing care)	51	1	1	0	0
Discontinuation/shut down of services (e.g. doctor visits)	74	1	0	0	1
Lack of access to medical support	68	2	0	1	1
Increased cost of care	34	2	0	1	1
Reduced support for PWD and/or CP	62	3	0	2	1
Increased inequities that existed before COVID-19	20	1	0	0	1
PWD and/or CP avoiding seeking help for health issues out of fear of getting COVID-19 in hospitals or doctor surgeries	65	2	1	1	0
Lack of information on what supports and services were available for PWD and/or CP during the COVID-19 pandemic	64	5	0	3	2

CP Care partner; PWD person with dementia
Highlighted in yellow are the topics with the most votes within that stakeholder group

D.13 South Africa

In South Africa, the survey was translated into Zulu, one of the major local languages, and ethical approval was obtained from the University of Kwazulu-Natal Biomedical Research Ethics Committee (reference number BREC/00006373/2023). Recruitment focused on care partners and care professionals.

The survey was completed by 8 care partners and 8 health care professionals, of whom the majority were women and had some degree of difficulty with managing on income. Eight of the ten top priorities identified by South African respondents overlap with the priorities in the generic list. Additional topics that were prioritised, include difficulty managing control measures, PWD and/or care partner feeling hopeless, and financial uncertainties. Therefore, the generic research agenda is also relevant for South Africa, with the additional advice to take into account the financial situation of care partners in future research and policy recommendations.

Table 17. Number of times a topic was prioritised in South Africa compared with the generic list

	Generic List	South Africa		
		Overall	Carer	Professional
Diet or appetite changes of PWD and/or CP	89	6	5	1
Sleep disturbances for PWD and/or CP	142	13	7	6
Worsening physical health of PWD and/or CP	151	9	4	5
Faster cognitive decline of PWD	197	9	3	6
Increased use/dose of medications by PWD	47	2	1	1
PWD has difficulty understanding the COVID-19 situation	113	7	3	4
CP have difficulty managing COVID-19 control measures in context of PWD not understanding the situation	85	8	5	3
Increased anxiety/stress of PWD and/or care partners	182	12	7	5
PWD and/or CP feeling hopeless (e.g., feeling discouraged, loss of purpose, feeling the pandemic will never end)	74	8	2	6
Mood changes of PWD and/or CP (e.g., increased depression, sadness, mood swings)	139	8	5	3
Experiencing grief (PWD and/or CP)	55	1	0	1
Concerns about health of PWD	98	8	4	4
Concerns about health of CP	51	1	1	0
PWD and/or CP concerns about health of family and friends	12	0	0	0
CP fears of struggling to cope due to COVID-19 measures	34	1	0	1
PWD and/or CP concerns about the future	46	0	0	0
Increased behavioural problems of PWD	111	8	5	3
Increased social isolation of PWD and/or CP	171	12	4	8
Changes in quality of life and/or life satisfaction of PWD and/or CP	83	1	0	1
Increased care burden and/or responsibilities of CP	119	7	4	3
Positive/negative coping strategies used by PWD and/or CP	32	3	0	3
Changes in the quality of relationships for PWD and/or CP	47	4	2	2
Changes in social contacts of PWD and/or CP	58	6	2	4
Increased stigma experienced by CP during pandemic	7	0	0	0
Loss of work/change in work of CP due to COVID-19 measures	34	3	1	2
Interruption of physical and/or social activities of PWD and/or CP	57	0	0	0
PWD having reduced personal care	39	2	2	0
Increased time CP spend caring for person with dementia	46	3	2	1
Financial uncertainties/difficulties for PWD and/or CP	53	9	7	2
CP experiencing guilt over not being able to visit PWD	22	0	0	0
Difficulty accessing basic needs (e.g., shopping, accessing care)	51	5	5	0
Discontinuation/shut down of services (e.g. doctor visits)	74	6	4	2
Lack of access to medical support	68	3	0	3
Increased cost of care	34	2	1	1
Reduced support for PWD and/or CP	62	3	3	0
Increased inequities that existed before COVID-19	20	4	1	3
PWD and/or CP avoiding seeking help for health issues out of fear of getting COVID-19 in hospitals or doctor surgeries	65	7	2	5
Lack of information on what supports and services were available for PWD and/or CP during the COVID-19 pandemic	64	3	1	2

CP Care partner; PWD person with dementia
Highlighted in yellow are the topics with the most votes within that stakeholder group

D.14 UK

In the UK, the survey was considered a consultation process rather than research and therefore did not require approval from an ethics review board in the UK. The survey was distributed through formal and informal networks, organisations and institutions that support, research and engage with people living with dementia, cares and professionals. In total, 15 responses were received - 6 people with dementia, 1 care partner and 8 care professionals. We believe that the research agenda identified above is adequate for the UK for people with dementia and professionals but a limitation is that it lacks the views of care partners in the UK as well as those living with rarer forms of dementia (e.g. VaD, LBD, FTD).

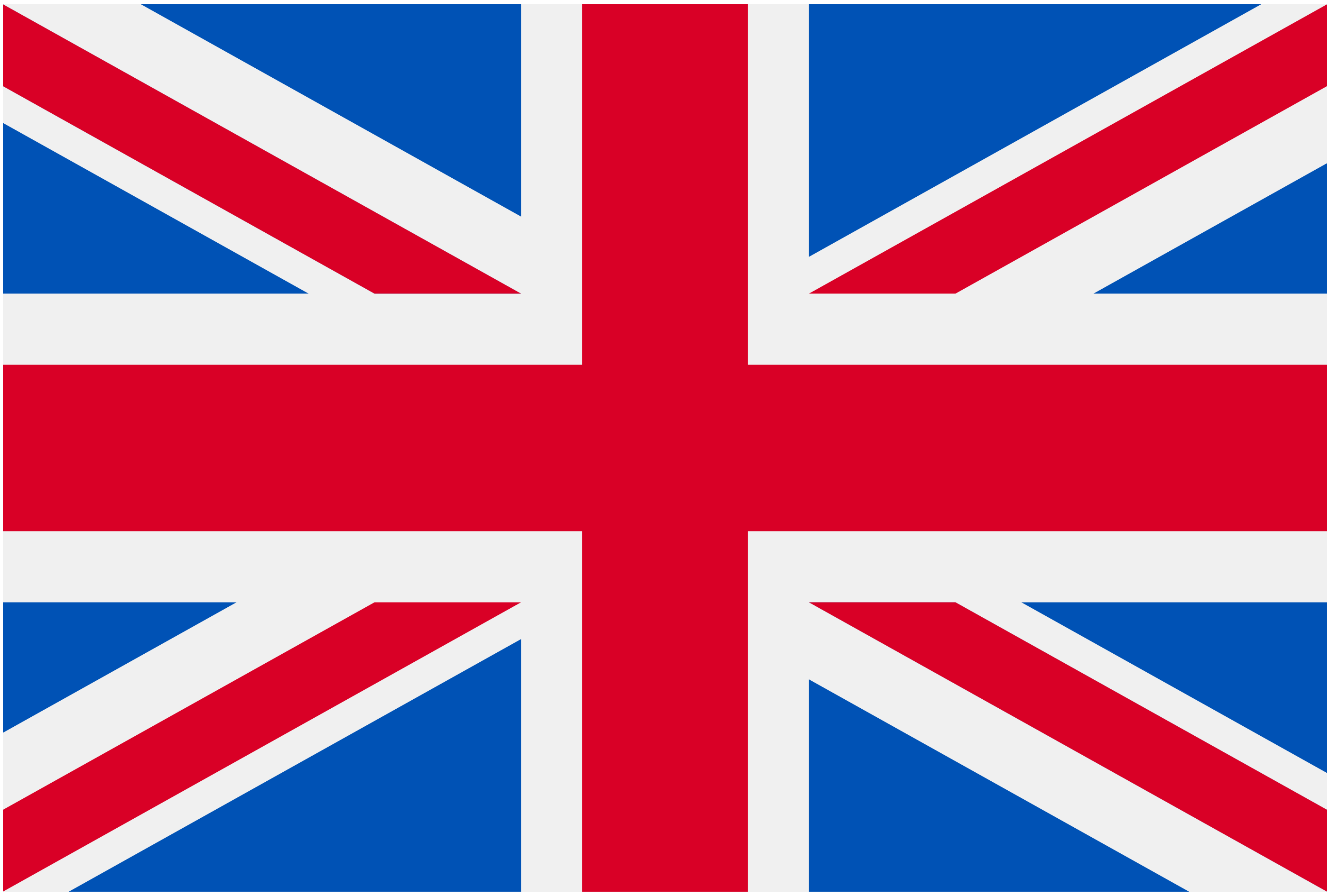

Table 18. Number of times a topic was prioritised in the UK compared with the generic list

	Generic List	UK			
		Overall	PWD	Carer	Professional
Diet or appetite changes of PWD and/or CP	89	4	2	0	2
Sleep disturbances for PWD and/or CP	142	6	5	0	1
Worsening physical health of PWD and/or CP	151	8	2	1	5
Faster cognitive decline of PWD	197	15	2	0	13
Increased use/dose of medications by PWD	47	0	0	0	0
PWD has difficulty understanding the COVID-19 situation	113	5	2	0	3
CP have difficulty managing COVID-19 control measures in context of PWD not understanding the situation	85	7	1	1	5
Increased anxiety/stress of PWD and/or care partners	182	10	5	2	3
PWD and/or CP feeling hopeless (e.g., feeling discouraged, loss of purpose, feeling the pandemic will never end)	74	5	4	0	1
Mood changes of PWD and/or CP (e.g., increased depression, sadness, mood swings)	139	9	7	0	2
Experiencing grief (PWD and/or CP)	55	5	2	0	3
Concerns about health of PWD	98	2	2	0	0
Concerns about health of CP	51	1	0	0	1
PWD and/or CP concerns about health of family and friends	12	1	0	0	1
CP fears of struggling to cope due to COVID-19 measures	34	2	0	0	2
PWD and/or CP concerns about the future	46	1	1	0	0
Increased behavioural problems of PWD	111	10	3	0	7
Increased social isolation of PWD and/or CP	171	16	5	0	11
Changes in quality of life and/or life satisfaction of PWD and/or CP	83	5	2	0	3
Increased care burden and/or responsibilities of CP	119	4	1	0	3
Positive/negative coping strategies used by PWD and/or CP	32	0	0	0	0
Changes in the quality of relationships for PWD and/or CP	47	2	0	0	2
Changes in social contacts of PWD and/or CP	58	2	1	0	1
Increased stigma experienced by CP during COVID-19 pandemic	7	1	0	0	1
Loss of work/change in work of CP due to COVID-19 measures	34	0	0	0	0
Interruption of physical and/or social activities of PWD and/or CP	57	8	3	0	5
PWD having reduced personal care	39	1	0	0	1
Increased time CP spend caring for person with dementia	46	4	0	1	2
Financial uncertainties/difficulties for PWD and/or CP	53	1	1	0	0
CP experiencing guilt over not being able to visit PWD	22	3	1	1	1
Difficulty accessing basic needs (e.g., shopping, accessing care)	51	4	1	1	2
Discontinuation/shut down of services (e.g. doctor visits)	74	8	4	1	3
Lack of access to medical support	68	6	2	0	4
Increased cost of care	34	1	0	0	1
Reduced support for PWD and/or CP	62	4	1	0	3
Increased inequities that existed before COVID-19	20	2	0	1	1
PWD and/or CP avoiding seeking help for health issues out of fear of getting COVID-19 in hospitals or doctor surgeries	65	8	3	1	4
Lack of information on what supports and services were available for PWD and/or CP during the COVID-19 pandemic	64	5	1	1	3

CP Care partner; PWD person with dementia
Highlighted in yellow are the topics with the most votes within that stakeholder group

APPENDIX E. REFERENCE LIST

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