The COVID-19 on users of Long-Term Care services in Spain

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(with thanks to Aida Suárez-González who covered the section related to dementia)

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1. Impact of COVID19 on long-term care users and staff so far

1.1. Number of positive cases in population and deaths

Spain is one of the countries most affected by COVID-19 on a global scale. According to data provided by the Spanish Health Ministry, as of the 28th of May, there have been a total of 237,906 cases of COVID-19, 123.804 people are been hospitalised and 27,119 have died [1]. The excess of deaths as per 28th of May is 43,202 according to the registers from the MoMo system [2].

Older people have been the most severely affected by COVID-19: the case fatality rate amongst people between the ages of 70 and 79 has been 14%, and 21% for people older than 79. According to data where the age of the patient is known, people over 70 years of age comprised 37% of all known COVID19 infections, 48% of all hospitalisations, 33% of ICU patients and 86% of mortal victims [3].

1.2. Rates of infection and mortality among long-term care users and staff

Available data on the impact of COVID-19 amongst users of long-term care refer mainly to mortality in nursing homes. Figures relating to the number of home care users who have been infected, hospitalised or who have died have not been made public, except in some regions such as Cantabria[1]. In contrast to the situation in healthcare where the number of staff in the health service affected by the illness have been collected, there is no equivalent data collection for social services staff information, or at least no systematic data collection. As a result, the impact of COVID-19 on staff working in long-term care services cannot be estimated.

On April 3rd, the Spanish Ministry of Health required that every regional government provide standardised data on deaths in care homes to provide national and regional comparative data and understand the full impact on the care home population in Spain. The data that each community is required to send to the Ministry every Tuesday and Friday are as follows:

- Total sum of deaths in care homes from the 8th of March, 2020 to the present date.
- Total sum of confirmed COVID-19 deaths in the nursing home from the 8th of March, 2020 to the present date.
- Total sum of deaths with symptoms that are compatible with COVID-19 (not confirmed) in the nursing home from the 8th of March, 2020 to the present date.

Despite this requirement, the Health Ministry has not yet released these figures. All of the available information comes from media [5] and regional governments. Although the information provided by regional governments has been progressively standardized and clarified, the data are not yet completely comparable: some regions differentiate between deaths of people who have been diagnosed through a positive test (PCR) with COVID-19 and

[1] According to data provided by the regional Government of Cantabria, 797 SAAD records were closed due to death between March and April 2020, while the average for the past 4 years is 566. 600 of these 797 people were in receipt of long-term-care: 55% of were from residential care and 45% were receiving home care [4].

deaths of those with symptoms of the illness but who have not been tested, while other regions do not make that distinction. In the latter case, the only way of differentiating between deaths of confirmed and deaths of non-confirmed cases, in order to reach comparable figures, is to review death certificate entries and/or health records, a time-consuming process. In addition, some regions, but not all, have included deaths in care homes for adults with disabilities or mental illness in their data.

According to the latest data published in the media (collected directly from 'sources' within regional governments) a total of 19,194 people have passed away in care homes (26th of May) [5]. This number includes both the deaths of people who have been diagnosed with COVID-19 and the deaths of those with symptoms of the illness but who have not been diagnosed. These deaths are quoted as being equal to 70% of all COVID-19 confirmed COVID-19 deaths in Spain but this estimate is invalid, because currently the official data on COVID-19 mortality in Spain provided by the Ministry of Health (used in the calculations presented in the media) only counts cases confirmed via a diagnostic test (PCR or antibody testing) [6].

The media report cited does however distinguish between deaths of people with confirmed and suspected COVID-19. Using only the figures of deaths of people in or from care homes with a positive test (last reported as 9,599 people), the number of deaths of care home residents would represent 35% of the officially recorded deaths in Spain. While this is a fair, like for like comparison, it does not adequately capture the full impact.

An alternative source of data is that collected by the funeral services, which captures all deaths occurring in the community. The regional government of Catalonia issued figures on the number of care home resident deaths on the 8th May 2020 which were double the number (which they gathered from funeral services) of deaths issued by the national Ministry of Health for this region [7].

The high mortality rate in nursing homes has created significant social and political concern. The Spanish Public Prosecutor's Office, via the Delegate Prosecutor, has opened 211 civil proceedings and 160 criminal proceedings related to the protection of nursing home users' individual and collective rights [8]. Regional authorities have intervened in a number of care homes either in response to their high number of deaths or as a proactive response to an infection outbreak, in response to guidelines issued. In Madrid, where the greatest number of deaths in care homes are believed to have occurred, the regional health department has intervened in 14 care homes. The high mortality rate in nursing homes has sparked a debate on both the general long-term care model and, more specifically, the residential care model, topics which were formerly almost absent from public opinion.

2. Brief background to the long-term care system

The management of the long-term care system falls to the regions or Autonomous Communities led by the regional governments, who are responsible for regulating, financing and providing these services, as well as for guaranteeing care quality. Local authorities also

intervene in providing these services, however, their capacity for intervening is inferior to that of the regions and they are limited to providing specific services, namely home care [9].

The role of central government in the field of social care services is minor, since it does not take on any regulatory functions, nor does it provide services. Nonetheless the central government dictates the financial and regulatory functions for the National Long-Term Care System (SAAD), which is provided mainly through the regional Social Services. Because of this, the long-term care field needs to take into account both nationwide regulations (which are linked to the benefits and services which make up the long-term care system) and regional regulations, which regulate the whole of the social care services and develop the long-term care system in each region.

The main services for people in need of long-term care are the following:

- Home care services
- Telecare services
- Day care centres
- Care homes (including supported living, residential and nursing homes)
- Cash payments for purchasing long-term care services
- Cash payments for personal assistance
- Cash allowances for carers

According to the Institute for the Elderly and Social Services (IMSERSO)[2]'s monthly data [10], the number of benefits and services financed by the national long-term care system is almost 1.5 million.

Service type	Number	%
Preventative services	63,928	4.5
Telecare	248,279	17.6
Home care	246,904	17.5
Day care	95,401	6.75
Residential/ nursing home care	163,429	11.6
Cash payments for purchasing services (direct payments)	153,889	10.9
Cash allowances for carers	432,522	30.6
Cash payments for personal assistance	7,971	0.5
TOTAL	1,412,323	100

[2] IMSERSO is an agency of the government of Spain responsible for the management of social services that complement the benefits of the Social Security System

Table 1: Number of services and benefits received as part of National Long-Term Care system (SAAD) April 2020

Service type	Number	%
Preventative services	63,928	4.5
Telecare	248,279	17.6
Home care	246,904	17.5
Day care	95,401	6.8
Residential/ nursing home care	163,429	11.6
Cash payments for purchasing services (direct payments)	153,889	10.9
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Cash payments for personal assistance	7,971	0.5
TOTAL	1,412,323	100

Considering that a person can be the recipient of several benefits or services, the number of users of one or several benefits is 1,114,124, or 2.3% of the population. Amongst the population over 65 years old, the number of benefit users is 805,202, or 8.8% of that population.

The number of people in receipt of some form of long-term care is however substantially larger, as services are also provided outside of the national long-term care system (SAAD). This is mainly because they either do not fulfil the requirements for accessing the system, or because they have not been assigned any services or benefits, even if they do fulfil said requirements. Due to this, and according to IMSERSO's data, the number of users of the main services for elderly people is about two million people [11].

Table 2: Total numbers of main long-term care users (2018)

Telecare	942,446
Home care	451,507
Day centres	67,930
Residential/ nursing home care	280,317

The Spanish long-term care system's relatively important shortcomings were evidenced before the epidemic. Briefly, the following can be pointed out:

- Lack of development in preventive care and home care, partly due to the shortcomings of primary care social services, which are managed by local authorities[3]. The Home Care

[3] Primary attention social care services or basic social care services make up the first level of attention in the social care service system. They mainly offer information, orientation, assistance and attention in the home, from a community care perspective.

Service does not generally respond to the needs of people with moderate or severe care necessities who live in their own homes.

- Lack of coverage and intensity of public services, aggravated by the existence of large numbers of people who qualify for long-term care but who are unable to access to any service. Waiting lists to receive benefits are still a pressing issue nationwide and at a regional level. Figures suggest that as much as 33% of all people with a right to receiving benefits are awaiting access [12].
- Shortcomings in the support available to family/ unpaid caregivers.
- Severe inter-regional disparities when it comes to the quality, coverage or funding of services, which creates clearly unequal long-term care models [13].
- The complex and, to some extent dysfunctional, structure of the long-term care system has contributed to developing the long-term care system insufficiently and unequally. [14].
- An excessively high number of people receive cash allowances to family caregivers in lieu of services (framed as benefits for the wellbeing of family caregivers), compared to in-kind services. Although this has reduced over time, cash allowances to family caregivers still make up 30% of all services [12] [13]. This contravenes their intended use, as an exceptional resource, given that the SAAD system was created with the aim of to strengthening professional long-term care services and reducing the burden on caregiving families.
- The prevalence of cash allowances for family caregivers has heightened the responsibility of families in caregiving. At the same time, as it largely not monitored, it has likely driven many families to seek private care, which is mostly provided by migrant women hired with no legal contract [15].
- Issues related to funding: the total public spending destined towards long-term care services is low [12], the share of funding from the central Government is less than what was anticipated [13] [16] and out of pocket payments levels are high, especially for those with medium and high incomes.
- This low public spending is related to the low wages in long-term care sector. The monthly cost per member of staff in the sector is 1,410 euros, 67% of the average wage per worker in Spain. In fact, poor labour conditions are the norm in a sector where women are the majority. In care homes, staff ratios vary markedly between regions and are generally inadequate [17][4].
- When it comes to limits in public spending, a number of public services are provided by private entities, both for and non-profit. Furthermore, in both cases public funding is

[4] Professional ratios vary for people with medium and high assessment grades for long-term care needs: they are as low 14 workers for 100 users in Extremadura and as high as 40 in Gipuzkoa, where the hourly income (13,0 euros) almost doubles the nationwide average (7,6) [18].

insufficient. The average total price paid for a bed in a private care home by public administration (irrespective of any user co-payments) is around 52€ per day [11]. It is widely believed that the amount paid is reflected in the lack of quality of care.

- Public administrations have difficulties when it comes to inspecting, evaluating and controlling responsibilities. In the care home sector, marketization has led to an increase in the available places, however it is believed that this has been at the expense of the quality of services, above all through creating poor labour conditions which make it more and difficult to control and coordinate care to ensure quality [19].

3. Long-term care policy and practice responses to COVID-19

3.1. Whole sector measures

One of the first general measures the Government of Spain set up in the field of social care services was the creation of an Extraordinary Social Fund of 300 million euros to help with COVID-19 related needs. This fund's resources were to be transferred to regions and could only be used to help with COVID-19 related needs. It was designed to finance staff and projects such as:

- Strengthen home care services.
- Increase the number of telecare devices and improve their quality.
- Move rehabilitation services to home care, when necessary.
- Strengthen homeless outreach and engagement efforts.
- Reinforcing preventive measures.
- Hiring more staff for social services and residential centres.

Most of these measures are directed towards elderly people. However, the Social Fund can be used for any policy which regions consider essential and urgent in order to care for those who are most vulnerable during this crisis.

The COVID-19 crisis has also created some changes in the way social care services and long-term care services organise their various roles and responsibilities. At the start of the crisis, the Health Ministry assumed responsibility over a large number of public policies (excluding those relating to Defence, Home Affairs and Transport) which included those related to social services. As a result, nursing homes have gone from being in the field of social services to being in the field of health in certain regions [20] [21].

Furthermore, the Government established certain measures for social service workers, such as the possibility of imposing extraordinary services, exemption from certain mobility restrictions, and assignment of responsibilities different from those in their job description, including direct

care tasks. Exceptional measures have also been put in place for hiring or reincorporating staff, such as exemption from certain qualification requirements for new recruits [22].

3.2. Care coordination issues

3.2.1. Hospital discharges to the community

Discharge procedures for moving COVID-19 patients that normally live in their own homes have depended upon the individual's available support structure (taking into account limitations on non-resident relatives visiting due to the quarantine measures), and the feasibility of providing adequate post discharge support at home. Certain regions have decided to use hotels to house elderly people who require a period of convalescence and/or who are users of nursing homes where the established social distancing measures cannot be respected [23]. In some areas, integrated care or "hospital-at-home" [24] has provided a vital role in ensuring safe discharge to the community and home-based treatment and rehabilitation [25] [26] [27] [28].

3.2.2. Hospital discharges to residential and nursing homes

The guide for the prevention and control of COVID-19 in nursing homes and other residential centres indicates that if a resident has been hospitalized they may be returned to their established care home, or newly admitted to a care home, even if their PCR is still positive [29]. However, the policy states that such action should be contingent on the person being isolated and monitored in the home for 14 days starting on the day of discharge, or until they have a negative PCR test comes back negative, and the home having the capacity to meet these conditions. In practice, many froze new admissions.

As an alternative to returning to a person's usual care home, some regions facilitated rapid access to care allowances to family members and other services and technical help to allow some families to bring their relatives home after discharge [30] [31], whilst stipulating the usual requirements for a period of quarantine [32].

3.2.3. Referral to hospital from care homes

The healthcare which people who live in residential centres receive varies substantially, even within a single region [33]. During the COVID-19 crisis, few people have been transferred from residential centres to hospitals, given the saturation of the latter, which has been widely criticized[5].

According to information provided by the media, a protocol was initially put in place in the Community of Madrid which vetoed the possibility of adults with disabilities being moved to hospitals. A second protocol established the possibility of going ahead with transferring care

[5] For example, in the case of Castilla y León, almost three out of four people who passed away of coronavirus in nursing homes were not moved to a hospital [34].

home residents infected with COVID-19 in order to to “guarantee quality care to residents”, but without endangering the “sustainability of the Health System, avoiding the dire consequences of its collapse” [35].

The Ministry of Health protocol which specifies the management of COVID-19 in care homes does not define the grounds for hospitalisation (a decision which needs to be taken by a medical doctor), but it does underline the expectation that care homes are to be expected to care for any residents with COVID-19 that do not require hospitalisation (and sets out the measures to be taken to prevent contagion within the home) [29]. The Spanish Geriatric and Gerontological Society has advised that hospital admission should be avoided, if possible [36]. In some regions residents with COVID-19 symptoms have been referred to private hospitals [37].

3.3. Care homes (including supported living, residential and nursing homes and skilled nursing facilities)

3.3.1. Prevention of COVID19 infections

Background

To start with, the COVID-19 virus spread across the country at an alarming rate, affecting the ability of authorities to respond in a timely manner [38]. Despite widespread knowledge of the impact of COVID-19 on older people, and in particular the reported deaths rates in Italy, when the virus arrived in Spain, care homes were unprepared.

On the 5th March 2020 the central government issued a protocol stipulating the measures that care homes should take to prevent COVID-19 infection occurring and defining actions to be taken in response to a resident or member of staff becoming symptomatic which established grounds isolating residents within the care home. It also stipulated total limitations of visitors which was immediately enacted throughout Spain [39].

This protocol was rapidly disseminated, appearing on the day of its publication on major media platforms related to geriatric care or services for people with long-term care needs. Additional protocols specific to each autonomous administration were also published and disseminated at the regional level at a similar time. Nevertheless, the initial protocol was published 9 days after the first recorded cases in Spain. Within five days of these first cases being recorded there were officially diagnosed COVID-19 cases in almost every region of Spain [38].

Many residents became infected within the following fortnight, despite the early recommendations and it is likely that many factors contributed to this such as [38]:

- The time lag between first officially diagnosed cases and the release of the initial guidelines to prevent the spread of infection.
- Specific weaknesses within measures taken, such as: only focusing on the isolation of symptomatic residents initially; or the length of time it took to clarify how the relevant

departments within the autonomous administrations should respond to the challenges being faced in care homes.

- Lack of PPE for care home staff (widely reported and likely to have made it impossible to follow parts of the protocol), and lack of clarity over whose role it was to provide PPE to care homes.
- Limited access to diagnostic testing combined with ambiguity over whose role it was to test care home residents or staff; and ambiguity in relation to who should be tested.
- Underlying organisational unpreparedness on the part of care homes to adhere to the initial protocols. In the spotlight that has been put on care homes, discussions have raised all of the following factors which may have played a role: i) physical capacity (double occupancy of rooms is still common place in Spain, and the physical structure of much of the care home stock is believed to be incompatible with zoning techniques to minimise infection spread); ii) inadequate medical support not only as residents became ill but predating the crisis, due to poor integration of health care in care homes believed to have knock-on effects for the physical wellbeing of residents at the outset of the crisis, and on the competence of care home staff for dealing with an acute health crisis in situ; iii) staff capacity (low-level training; highly variable ratios between different regional administrations with potential loopholes [17] and weak regulatory/inspection systems to ensure compliance); and finally iv) managerial competence for dealing with an unprecedented crisis.
- Inadequate funding affecting aspects described above. Whilst the cost of providing care has increased, Spanish Government funding (which should meet 50% of the cost of publicly funded care home places - the other 50% paid by the autonomous administrations), has remained static.

All the initial evidence of the crisis occurring in care homes came from media sources. A turning point came when stories of residents being found “dead in their beds” in a care home in Madrid appeared in the Spanish press on the 19th March and was picked up by media across the world. It quickly became clear that that, while the event picked up in the press was an extreme occurrence, the extent to which COVID had spread among care homes was widespread.

In Spain, Catalonia is the region with the greatest number of care homes (1,006) followed by Castilla-Leon (810), Andalusia (665), Madrid (474) and Castilla La Mancha. By 26th March, some three weeks after the release of the protocol stipulating the measures that care homes should take to prevent COVID19 infection, there were early (unofficial) reports suggesting that 11% of care homes in Castilla-Leon, and 23% in Castilla La Mancha had cases of COVID19 [40]. Soon after figures started to emerge for Madrid and Catalonia, the most densely populated areas in Spain, indicating that they were the most affected areas.

This awareness resulted in the publication of a series of new regulations announced via the Official State Bulletins (BOEs), starting on the 21st March 2020 [41].These defined legally binding measures to be taken by the regional administrations with the aim of halting the spread of infection among care home residents and care workers. They were released in tandem with updated recommendations describing in greater depth all the measures that care

homes should take to minimise the risks of COVID-19 and deal with any infections (24th March 2020) [29].

Much of the measures taken have been cumulative, with subsequent regulations announced in further BOEs largely building on former specifications. However there is some lack of consistency, notably between the early protocols and later measures stipulated. While this represents adjustment to emerging evidence both nationally and internationally, we have tracked the measures to provide insight into the evolution of preventative measures.

Initial measures designed to prevent COVID-19 infections among residents

The initial recommendations to care homes published on the 5th March [39] specified general precautionary measures (such as hand-washing between each and every contact with a resident, heightened cleaning and disinfection within the home, particularly of frequently used surfaces, and procedures for waste disposal). None of these have since changed. It also specified actions to be taken in the event of a suspected or confirmed infection among residents or staff members (see later), some of which has changed over time.

Initial measures designed to prevention the spread of COVID-19 from care home staff to residents

In relation to **staff**, the initial guidelines [39] specific to care homes stated only that staff presenting with upper respiratory infection symptoms should be assessed by primary care services to determine whether they could remain at work or not.

The initial recommendations for care homes [39] also did not specify where to contact in the event of suspected cases, difficulties maintaining staffing levels, lack of personal protective equipment or any of the situations likely to be arising.

3.3.2. Controlling spread once infection is suspected or has entered a facility

Initial protocol

With respect to **residents**, the early protocol specified that isolation of residents and use of PPE was only required if residents were symptomatic, with COVID-19 symptoms (described as a high fever, cough and difficulty breathing), but no actions were indicated for *potential* cases such as situations when the resident that had been in close contact with the person.

The protocol for PCR testing was also limited, referring only to testing of all probable cases that are hospitalized or meet the criteria for being hospitalised.

Regarding potential infection among **staff**, the early protocol indicated that anyone with possible symptoms working in health or social care or any essential service should be tested [39].

Separate guidelines from the Ministry of Health issued on the 15th March (not specific to care homes) stipulated that *any* person (including health and social care staff or family members) that have provided care to anyone categorised as a possible, probable or confirmed case without using "adequate means of protection", or been at less than 2 metres distance from someone categorised as a possible, probable or confirmed case for 15 minutes or more, should remain in quarantine for two weeks [42]. No specifics were given related to priority for testing to allow for swift return to work. This potentially contributed to rising staff shortages.

First legally binding requirements

The order SND/265/2020, of the 21st March 2020 [41] made clear that if more than one case of COVID-19 occurred in a care home, the autonomous administrations were to ensure that every care home affected should submit information stating the number of residents in the care home falling within the following categories:

a. Residents without notable symptoms and without having had close contact with a known or probable case of COVID-19 infection.

b. Residents without symptom in isolation as a preventative measure following close contact with a known or probable case of COVID-19 infection.

c. Residents with symptoms compatible with COVID-19 infection.

d. Formally diagnosed cases of COVID-19 infection.

In addition to these groups, any residents with minor upper respiratory tract infections were to be isolated.

With these instructions, the order SND/265/2020 shifted the focus of isolation from residents that were only symptomatic (according to the described symptomology of COVID-19 infection), to isolation of possible, probable or confirmed cases, thus including a cohort of asymptomatic residents deemed at risk of having contracted the infection, a measure more in line with emerging international evidence.

In line with this shift in approach, and in consideration of the space constraints and the logistics of caring for residents isolated in single rooms, the order SND/265/2020 also identified that isolation of residents could be provided in cohorts (known, probable, possible cases); ideally with each group located in a specific zone of the care home.

Other defining features of the order SND/265/2020 were specifications that medical personnel, nurses and other health care workers could be employed to provide assistance in care homes; and that Primary Care health centres would be responsible for providing a coordinated medical response to care homes within their reference area, while the regional health authorities were to establish procedures to track the evolution of cases in care homes.

Updated legal measures

Further consolidated legal directives were published on the 24th March and later amended on the 4th April [43].

In its first instalment one of the notable developments was a decree that all care homes were to be considered essential services under the general order relating the national state of alarm. Regional authorities were also given the freedom to insist on admission, discharge or transfer of residents in any care homes −regardless of their public or private ownership− in order to meet with the criteria for isolation of different categories of resident (non-symptomatic, possible, probable or confirmed COVID-19), or to respond to crises in staffing levels.

It stipulated that the management of each care home was now *legally obliged* to provide information on the physical characteristics of the care home and of the characteristics of staff and residents, as per the guidelines in the preceding orders published on the 21st March [41], according to the time scales dictated by the autonomous authorities. The updated legal measures also prohibited care homes from closure or the reduction or suspension of normal activity in relation to the situations arising during the pandemic.

The same order also informed care homes for the first time that they were legally subject to health inspections, and that in the case of housing formally diagnosed cases of COVID-19 infection, the health authority was permitted to covert the premises to a health care establishment and take over its general management.

In addition, regional authorities were informed that they were required to assign a case worker to care homes in any cases of unanticipated increase in number of deaths, or other exceptional circumstances. The latter were categorised as situations where it was: i) impossible to adopt the preventative measures required due to lack of staff, protective equipment, physical (space) constraints, ii) impossible to manage the removal of deceased residents due to a lack of funeral services, iii) any other circumstance which presented a grave risk to the integrity and sustainability of the service. The order also stipulated that care homes were also obliged to inform of such circumstances, underlining the extent to the which the regional authorities rely on the compliance of care homes to meet their obligations (and vice versa).

Finally it was clearly stated that “non-compliance or resistance to the orders” by the regional authorities in the aforementioned areas could result in legal sanction.

Additional general legal measures specified on 4th April 2020

A subsequent order [6] also underlined that regional authorities should prioritise PCR testing of residents, and the provision of protective equipment, as a minimum in the case of care homes falling into categories c and d.

Regional authorities’ legal responsibility to *ensure* that the combined measures (described previously) to prevent the spread of infection were undertaken in care homes.

The legislation also set out that regional authorities were legally obliged to submit information to the national Ministry of Health on the situation in care homes, starting on the 8th April 2020

and every Tuesday and Thursday thereafter (Table 3) – a responsibility which relies on the communication between care homes (who are also now legally obliged to comply), and the regional administrations. To date many autonomous authorities have yet to publish their data with some notable exceptions including Asturias [44], Cantabria [45], Navarra [46] or Madrid [47]. Catalonia, the region with the greatest number of care homes is still corroborating its figures with information on death certificates [7].

Table 3: Information that the regional administrations of the Spanish autonomous communities must provide twice weekly to the Ministry of Health on the situation in care homes

1. Number of care homes in the Autonomous Community
2. Current number of residents in care homes in the Autonomous Community
3. Number of deaths of residents confirmed to have COVID-19 up until [the date]
4. Number of deaths of care home residents suspected as having COVID-19
5. Number of care homes where intervention by the regional health department has taken place in relation to cases of COVID-19 from 24th March up until [the date]
6. Number of staff currently working in care homes where intervention by the regional health department has taken place in relation to cases of COVID-19 from 24th March up until [the date]
7. Number of deaths since the 8th March 2020 up until [the date] where intervention by the regional health department has taken place in relation to cases of COVID-19

Final consolidated legal measures specified on 4th April 2020

A further order [6] also published on the 4th April 2020 consolidated the one published on the 24th March [43]. This mostly underlined previously detailed requirements, but notably informed that the competent authority in each autonomous administration should now prioritise PCR testing of residents and staff in care homes, as well ensure the availability of protective equipment, at the very least in care homes falling into categories c) and d), i.e. with diagnosed or suspected cases.

3.3.3. Managing staff availability and wellbeing

Early guidelines [39] published at the beginning of March recommended the use of PPE with symptomatic residents, and specified that staff presenting with upper respiratory infection symptoms should be assessed by primary care services to determine whether they could remain at work or not.

These were overruled by new rules stipulated in the order published 21st March [41] stating, somewhat ambiguously, that “every worker in contact with residents must take the recommended protection according to the level of risk they are exposed to”. What was clearer was the requirement that “the number of staff in direct contact with possible or confirmed COVID-19 cases must be reduced to a minimum as well as their amount of exposure time”.

The same legal guidelines stated, with respect to care workers, or other health care staff that in the event of close contact with a possible or confirmed case, only vigilance for the appearance of symptoms was required, and that "normal activities could be continued". This, confusingly, contradicted a message on the need to quarantine staff at risk of spreading the infection contained in a protocol issued by the Ministry of Health [42].

There are no specific guidelines for testing of care home staff other than the details of the order published on the 4th April [6] stating that the competent authority in each autonomous administration should prioritise PCR testing of residents and staff in care homes, as well ensure the availability of protective equipment, at the very least in care homes falling into categories c) and d), i.e. with diagnosed or suspected cases.

In response to staff shortages, the resolution published on the 16th April 2020 [48] made legal the employment of care workers lacking the generally required training certificate, whilst advising that preference should be given to people with former experience of care work, and stipulating that the employing agencies (care homes, or care worker agencies) would have to guarantee supervision and practical training on the job.

Some regions [49] have created platforms whereby ex care workers or health professionals or other members of the public with caregiving experience can be liked to care homes in need of staff, or regions implemented other plans to hire additional staff to strengthen the care homes capacity [50]. If a care home is deemed as requiring intervention, it can be staffed by health professionals, as described previously. In a few cases, staff have voluntarily moved into the home to prevent COVID-19 entering.

In care homes, there are reports of exhaustion and distress among staff, even in care homes which have remained unaffected [51], and lack of PPE. Many homes have resorted to home-made protective-equipment with official equipment only appearing to arrive towards the middle of April, according to local reports. Large and small charitable bodies have provided equipment, the Mapfre Foundation (of the insurance company Mapfre), having made a significant impact in the delivery of face masks in Andalusia [52], among numerous examples.

In order to comply with the measures to prevent the spread of COVID-19 care homes have had to employ extra ancillary staff as well as extra care workers. In Madrid, on the 28th April, the regional government announced that €624,000 were being directed to care homes to help pay for auxiliary services, catering and cleaning. This measure was announced 9 weeks after the first COVID19 case was confirmed in Madrid. In many regions, staff working in day centres, closed due to the pandemic, reinforced residential teams [53]. Some regions have offered special accommodation services to care home staff, so that they do not have to return to sleep at home [54].

There some accounts of psychological support services being provided for residential care workers [55] [56] [57], although it is far from clear that the practice has been widespread.

Recently the autonomous administration of Navarra has announced extra payments to care homes to compensate for the extra staff costs during the COVID-19 pandemic [58]. As yet, there are no reports of specific compensation being provided to care home staff.

3.3.4. Good practice examples

Amidst the crisis, the factors which contributed to it and the immense struggle to gain control, there have been some notable examples of good practice.

Rapid adaptation of hotels to provide “health hotels” for COVID-19 positive residents not requiring hospital or in-patient intermediate care was a key part of the protocol in Catalonia. Hotels were also converted to provide a safe environment for the isolation of non COVID-19 positive care home residents in other parts of Spain. Some staff in care homes [115] across the country voluntarily deciding to live-in during the lockdown to shield residents from infection.

As soon as visitors were banned, many care homes put in place measures to facilitate communication between residents and their families through phone calls, video calls, etc.[59]. A cooperative organisation in Andalusia called Macrosad has been particularly active during the crisis in supporting the care home sector [60]. They designed facial recognition units to detect if anyone entering the care home had a body temperature above 37°C and implemented it in two separate care homes. They have also designed metacrylate screens and ´spaces´ to facilitate safe visiting by family and friends (at the time of writing, still subject to the authorisation of the regional health authority). Finally, they created the initiative ´flowerpots of hope´ (*macetas de illusion*) in which the cooperative gifted a flower pot to every resident marked with messages of optimism and hope.

Other examples include coordinated voluntary support from youth organisations to create virtual links with care home residents (to play cards, sing, chat etc.) [61] and deliveries of tablets, supplied by local businesses, to permit virtual communication with residents [62].

Lastly, some organisations such as Macrosad have created online training courses for care home staff to train them on how to use PPE and other aspects of meeting protocols to minimise the spread of infection [60].

3.3.5. Provision of health care and palliative care in care homes during COVID-19

Relatively little is known about the provision of health care and palliative care in care homes during COVID19, which is an area which has caused concern among friends and relatives. It is worth noting that primary health care teams are not always responsible for providing medical support as at least half of the care homes in Spain sub-contract medical support, a situation which has previously led to debate about which guarantees the most equitable health care support for residents but never been put under the spotlight to such an extent as has occurred during the pandemic [63] [64].

In terms of the concerns of friends and relatives, there are two sides to this. Firstly, concerns have been expressed relating to lack of transparency in relation to the criteria used to determine how (and where) a care resident should be treated. Concerns have been raised of a lack of medical support, with the president of Federation of long-term care services (Federación

Empresarial de la Dependencia) that care homes had not been sent any medication other than sedation [65].

Secondly there are worries about how palliative care was actioned. Fuelled by media reports, many are asking, were care home staff sufficiently supported by primary care to recognise the need to action end of life care and prepare relatives in a timely manner? What palliative therapies were available? While it is known that primary health care staff were mobilised to support care homes, precious little is known about this process.

In Catalonia, local guidelines stipulated that medical assistance to care homes should be on hand 24/7 from primary health care staff. In addition, a protocol [66] was circulated on the 31st March 2020 in guide prescription of oxygen therapy for palliative care in care homes, although this was promptly – and unfairly − criticised in the press as evidence that the health authority had "given up on care homes". Intermediate care, hospital-at-home teams were also deployed to support care homes [67].

The situation in Spain seems to be divided between the worst affected and least affected areas. For instance, in Asturias, an area where the rate of infection among the general population remained very low, there were 209 deaths up until 27th May 2020, 81% of which took place in hospital. The regional health service (Servicio de Salud del Principado de Asturias, or 'SESPA') intervened and assessed all care homes, medicalised all those that needed it and supported many care homes with nurses from the SESPA.

Limitations on visits in palliative care situations have been a particular concern. By mid-April a number of autonomous authorities had published protocols to allow close family members to make a single visit to see a relative in a care home in an end of life scenario under strict guidelines regarding using of PPE, maximum length of visit and means of entering and exiting the home [68].

It seems that in the worst affected areas, the pressure on care home staff to respond to the palliative needs of residents and the experience of relatives will have been enormous. For instance in Madrid, a protocol published on the 5th May 2020 [69], states that the status of residents should be revised telephonically. Alongside the responsibility of care staff to ensure that permitted end of life visitors use PPE correctly and remind them of their obligation to "not impede health care" by strictly following the protocols, which it describes as intended to, "accompany the transition process, despite the difficult circumstances, minimising the isolation of residents at the end of life and reducing the sense of guilt among relatives for not being close to their family member." Staff were simultaneously reminded that supporting residents in their final days and family members during the process and after was vital to, "strengthen resilience [of family members and other residents], preventing psychosocial problems in the grief trajectory".

3.4. Community-based care

By law, as previously said, people requiring support within the community should have the options of: home care, day care services, cash benefits to family caregivers, cash benefits for

personal assistance services, or cash benefits for the independent purchase of home care, as well as other complementary and preventive services.

Home care is administered in two forms:

a. For people who are eligible to receive services according to the national evaluation criteria (the *Baremo de Valoración de la Dependencia* (BVD)), known as *Servicios de Atención a Domicilio* (SAD). Home care within this category is subject to a reference range in hours per month, per dependency level (3 levels). Falling under the national long-term care provision, SAD is co-funded by the autonomous administrations, local authorities (in some regions) and the central government.

b. As preventative services (*Servicios Sociales Preventivos* or *SAD social*) for people who do not yet meet the official criteria of being dependent, funded entirely by local authorities and is provided solely at the discretion of the regional or municipal authorities.

In 2012, 75% of home care provided in Spain fell into second category [70]. By 2015 it was 55% [14]. The prevalence of preventative services is partly explained by the inability to integrate residual low-intensity local home care services when the 2006 Spanish Dependency Law came into place [71]. The abundance of low-level services which do not serve people who are official classed as dependent has led to efforts to prioritise and define their role [72].

In relation to the official SAD home care, evidence suggests that the majority of regional governments do not provide the minimum number of hours of care prescribed per dependency level [73]. At such low levels of intensity, the home care provided as part of the official provision of long-term care offers very little to substitute for unpaid care.

Day-care services may be targeted at people with relatively high needs, or specific user groups (such as people with dementia), in which case they are frequently operated as a complementary service offered by large residential care homes; or they may form part of the locally-funded preventative care services, operating in nearby community centres, often run by third-sector organisations.

As described previously, cash allowances to family caregivers form a large proportion of the overall provision of long-term care in Spain via the *Prestación Económica para Cuidados en Entorno Familiar (PCEF)*. The level of benefit is significantly less than the value of in-kind services but there are no limits on how they are spent.

Aside from cash allowances to family caregivers, two other types of cash payment are available, more akin to direct payments in England or personal budgets in the Netherlands. Both offer amounts equivalent to the value of in-kind services, subject to assessed need [73]. The *Prestación Económica para la Asistencia Personal* (PEAP) provides funds to employ a personal assistant to provide support at home, while the *Prestación Económica Vinculada al Servicio* (PEVS) can be provided to purchase home care services independently. The PEVS is sometimes also provided to purchase a care home place if the person has been on the waiting list for a long time. The PEVS represents 10% of service provided in Spain, while the PEAP comprises less than 1% [10], with the majority provided in a sub-region within the Basque country (Gipuzkoa), mainly for older people, as an alternative to the PECEF. Disabled people continue to campaign

for the right to personal assistance services, and for a review of the way certain benefits are taken into account when calculating the PEAP on an individual basis which significantly reduces its potential value for people under the age of retirement [74].

Aside from these main service modalities, complementary services may be provided including home aids and adaptations known as *ayudas tecnicas,* meals at home*,* or telecare. The latter has proliferated in recent years as a result of extra funding being made available for its development.

There is very limited flexibility to combine services aside from the aforementioned complementary services. This is evidenced by the ratio of services to service recipient which currently stands at 1.27 [10].

3.4.1. Measures to prevent spread of COVID19 infection

Day care

At the start of the crisis all day centres were ordered to close to prevent infection risk. It is foreseeable that the centres will open in the coming weeks, within the de-escalation plans developed in all regions.

Home care

With the level of support provided through home care being so low and skewed towards "light services" [14], many local and municipal authorities cancelled a large proportion of home visits on the grounds that the risks to staff and service users outweighed the likely benefits, more often than not, leaving family members to cover for all other needs. Such decisions were taken, with a view to both the requirement to ensure that care workers must take the recommended protection according to the level of risk they are exposed to (something which was largely deemed impossible owing to the fact that protective equipment had not been provided), combined with concerns that home care visits may lead to dependent people most at risk from COVID19 being infected.

However the Ministry of Social Rights and 2030 Agenda issued recommendations for the delivery of home care during the COVID19 crisis on the16th March 2020 with a second version released on the 18th March [75]. This document stated that across Spain 450,000 people would normally receive some level of home care to provide necessary sport with daily life, while a further 100,000 would normally receiving some level of day care whose situation needed to be reviewed.

SAD home care is predominantly supplied via private home agencies, while much of the preventative home care services in Spain remain in-house. In the event of suspension of care on the part of private home agencies, social service departments were legally obliged to evaluate how to ensure continuity of service. Equally, home care agencies were instructed that services should never be suspended without informing the relevant administration.

The recommendations also stated that all visits for personal care and other activities of daily living must be continued – implying that services for instrumental activities of daily living (such

as shopping, accompanying people to get out the house etc. could be reviewed according to the individual's situation). One of the issues is that social service departments in Spain do not usually routinely review service users' situations and therefore most had limited information on hand (with the exception of some areas which have created local initiatives). The most likely source of knowledge on service user and families' situations would have been the organisations providing services. One of the recommendations from this document was, therefore, that all institutions and services involved work together to ensure that social services departments were alerted to cases of particular need. Finally, the guide states that continuity of service should be given irrespective of the grade of dependency of the service user, or the financing mechanism for services with emphasis on proving a flexible service, adapted to each individual situation, including providing more intensive care and/or a greater combination of services than would normally be permitted, such as combining telecare with food/ meal deliveries and other elements of direct care.

All staff from day care and other centres that had been ordered to close during the quarantine period, where expected to support this effort.

It was also stated that services should be provided to new clients without having to follow all the normal bureaucratic procedures including a full service user evaluation.

The recommendations suggested that **care delivery should be prioritised according to the following principles**:

- **Priority 1**: Special support to people in isolation at home due to COVID19 infection.
- **Priority 2**: "Intense continuing care" for non-substitutable activities, including personal care tasks that could not be carried out by anyone within the family network under professional support.
- **Priority 3**: Partial support in the case of limited networks of support, taking into the potential for support from neighbours, friends or family members.
- **Priority 4**: Care that could be substituted by telecommunication, with particular focus on alleviating the impact of social isolation.

Surprisingly, the recommendations do not explicitly refer to support from voluntary organisations as a means of providing substitute care.

Finally, any service user found to have symptoms compatible with COVID19 was to be accompanied until the health care services established whether or not they needed to be hospitalised or could be cared for at home.

As yet, the central government have not required regional authorities to document their home care activity during the crisis, or the use of substitutes with a view to capturing how these recommendations were acted upon, and understanding what logistical problems may have been experienced, or how solutions were found. It is also known that service users refused services for fear of contagion but it is not clear how many did so.

Nevertheless many of the devolved authorities responsible for organising and providing social care have posted information on their websites. In Barcelona, the second worst city affected in Spain, SAD home care remained active serving 12% of the usual user base [76] and also

mobilised a special team dedicated to supporting people known to have COVID19. The Andalusian regional government declared on its website that home care support would be guaranteed during the pandemic [77]. Some regions have intensified their home care programs, with more care hours and there are also widespread reports of substantial increases in the activity of existing home meal services, or, rather rapid creation of home meal services (a service which is relatively infrequent in Spain) [78] [79].

Telecare/ telecommunication

There are widespread reports of rapid expansion of telecommunication and telecare services to help compensate for the drop on face to face visits, a measure which has been promoted by the Spanish Association of Directors of Social Services in an official communication [80] and reinforced by recommendations from central government on the role of social services during the quarantine period [75] stating that specific efforts should be made to concentrate these on people affected by the closure of community centres, day centres and respite care.

There are widespread reports that regions and local authorities have strengthened their telecare services to serve people with long-term care needs living at home [81] [82] [82] both as a general measure and as a short-term substitute for home care (as described above). Some reports specify the level of service delivered [83], while others refer to plans to "increase and strengthen" [84] making use of the Extraordinary Social Fund, while others describe progress in meeting goals to deliver telecare, set out at the start of the crisis [85]. This information has been delivered through media reports, and announcements made by the regional administrations. It is impossible at this stage to estimate to what extent telecare coverage has increased overall during the pandemic.

Third sector collaboration

Where home care has operated at minimal levels, it has fallen to the third sector to fill in the gaps. As one of the most important third-sector organisation providing social services in Spain, the Red Cross [80] has attended more than 1,500,000 people with the support of 42,500 volunteers and the collaboration of 2,500 businesses. Actions taken include: transferring 8,000 people to hospital, installation of 21 temporary hospitals, delivery of medicines to 8,000 older people under the authorisation of the Ministry of Health and in collaboration with the Spanish Pharmacy School, 610,000 calls to provide preventative health care, 3,600 proactive interventions to reduce social isolation and provide psychosocial support and attending to over 4,400 callers to the helpline "I am listening" with psychological and social needs.

The Andalusian cooperative Macrosad [60] also launched telephone support to people at risk due to the suspension or reduction of home care services, making over 53,979 calls and providing 792 sessions of psychological support to service users and family members.

The Red Cross and Macrosad are examples of high-profile third sector organisations in Spain. There are huge numbers of much smaller organisations operating at a local-level for which much less information is available that have also played a critical role during the crisis.

On the 16th April 2020, the Ministry of Social Rights and Agenda published recommendations on of voluntary action during the COVID19 crisis [86]. This provided recommended steps to optimise voluntary action; a framework for the rights and responsibilities of voluntary organisations; and responsibilities of volunteers. The latter stipulated that volunteers must observe the necessary means of health and safety; observe social distancing rules and avoid unnecessary risks. It also indicated that the responsible authorities should provide PPE required to carry out tasks safely and that volunteers should not work if they have symptoms compatible with COVID19, are in quarantine, or are known to have had contact with an affected person.

Personal assistance services

According to reports from the European Network on Independent Living (ENIL), there have been no guidance or specific measures targeting disabled people who have personal assistance and live independently [87]. The few Centres for Independent Living (OVIs) that manage independent living and personal assistance projects in Spain have complained of a lack of communication from the autonomous administrations on which they depend. A few OVIs were asked by autonomous administrations to communicate positive cases among users and personal assistants.

Private care at home by domestic workers or by a compensated family member

Many people in Spain receive support in the home from a privately contracted "domestic worker", and many others receive care solely from a family member receiving the *Prestación Económica para Cuidados en Entorno Familiar* (PCEF), which comprises 42% of all state-funded services in Spain. None of the official documents relating to social and health care provide any specific measures to be taken to support these realms of care, although some areas report efforts taken to reach these groups.

Nevertheless, many local authorities launched campaigns to contact older people who live alone or who had long-term care needs by telephone [88] [89]. Such may have reached some receiving support in the home from a privately contracted "domestic worker.

In Asturias in the North of Spain, support targeted at people receiving the PECF was made available for food shopping and delivery of medicines. They also liaised with a University residence to provide support to and a third sector organisation (Arca de Noé) to support people in isolation. Integrated care was also provided through an active patient programme using video calls to support service users and caregivers with obstacles being encountered.

3.4.2. Managing staff availability and wellbeing

Home care

Recommendations published on the 16th March 2020 [75] stated that home care workers should not work if they had a fever, cough, felt short of breath or ´other´ symptoms. They should also "be wary with respect to the apparition of symptoms among members of their household".

All care workers attending to a probable or known case of COVID19 infection were to be equipped with PPE. Any care workers that attended to a person presenting with COVID19 compatible symptoms without PPE should immediately take time off work and remain in isolation. The guidelines neither specify the length of time for the isolation following contact with a possible case, nor do they make *any* specifications regarding PCR testing of care workers. This is likely to have resulted in many staff remaining off sick when they may have no longer presented an infection risk.

To help manage absenteeism, non-qualified staff could be hired. In addition, all staff from day care and other centres closed during the quarantine period were ordered support the home care/ care home related effort, for example by undertaking phone calls.

Support provided through personal assistance

Regarding personal assistants of people using the PEAP, there has reportedly been no provision for protective equipment for personal assistants (gloves, masks, disinfectant gel etc.), or for disabled people employing them, leaving responsibility to the people receiving services. Likewise no specific guidance has been provided on dealing with COVID-19 sick leave with personal assistants [87].

3.5. Impact on unpaid carers and measures to support them

The COVID-19 has produced a disruption in long-term care services such as day care centres and home care provision in Spain. Moreover, at the start of the pandemic some families decided to remove their loved ones from care and nursing homes over concerns of infection. This has led to a significant increase in burden care for families, who became the main care providers of care home residents that returned to live in private homes.

Measures of support issued from the central government

Four days after the announcement of the state of emergency, the Spanish Government issued a decree comprising the following measures to support unpaid carers:

1) MECUIDA plan. People with long term needs, many of them with dementia have lost an important source of daily support with the closure of day care centres. This support has come to be provided by families instead. A decree published on 18 March 2020 [90] by the Spanish government establishes that working carers who are able to prove new family care duties derived from the COVID-19 situation (e.g. closure of day care centres) are **entitled to request that their working conditions get adjusted or reduced,** with proportional adjustments in their salaries.

2) **Mortgage debt moratorium** for those who qualify as financially vulnerable, including: people unable to afford the payment of their mortgages as result of COVID can apply for a moratorium and families looking after relatives as a consequence of COVID-19 who needed to apply for the above plan MECUIDA, and experienced a substantial loss of

income that made it difficult to afford the costs of the mortgage can benefit from this protection measure.

Measures of support from town halls and the third sector

Some town halls produced support booklets and guides for unpaid carers, such as Madrid [91] or Gandía [92]. Other local social services as for instance Avilés [93] and Granada [94], provided psychological support services to unpaid carers through helplines and phone counselling services. The third sector has also produced guides and infographics to provide information and support to families, like for instance the non-for-profit organisations Fundación Matía[6], Plena Inclusión [95] and Federación de Mujeres Rurales [96].

3.6. Impact on people living with dementia and measures to support them

Population studies [97] suggest that the prevalence of dementia in people above 65 in Spain is between 4 and 9%, reaching up to 54% among those above 90. 88.6% of people living with functional dependency in Spain have dementia and up to 80% of all people living with dementia live in private homes and may rely on family care.

Effects of confinement

Experts have warned about the particular challenges of people with dementia under lockdown [98] [99] [100] and the media has highlighted the challenges faced by people living with dementia and their families as a result of confinement measures in Spain [101] [102] [103]. Interruption of previously well-established daily routines, reduction of social interaction, limited access to support, and restrictions on outdoor exercise and other pleasant and stimulating activities usually encountered outside the home, are among the disruptive changes brought in by the current situation. Disorientation, confusion, exacerbation of symptomatic and distressed behaviours and neuropsychiatric symptoms (delusions, hallucinations and agitation) are likely to emerge as result of these changes. Families also reported a significant worsening of cognitive and functional status during the lockdown. The Spanish Alzheimer's Association (CEAFA) reported that 200.000 people with dementia [104] had stopped receiving the specialised services provided by the local Alzheimer associations since the beginning of the lockdown.

Risk of infection and effects of hospital admission

The particular vulnerability of people living with dementia during the COVID-19 crisis has been highlighted by experts [105]. However, the Spanish Ministry of Health, in an official release, listed 7 groups of risk for COVID-19, one of them being people above 60, but did not refer to people living with dementia. There is no evidence that dementia itself increases the risk of infection or necessarily compromises survival in case of infection (unless perhaps in severe cases). However, someone living with dementia may be at higher risk of contracting the virus

[6] https://www.matiafundazioa.eus/es/documentacion-covid-19

because of greater difficulty complying with the safety measures due to their cognitive difficulties. In addition, it is well known that people with dementia who develop infections are likely to develop delirium which complicates hospital management and compromises the future cognitive health of patients. People with dementia also experience greater functional loss [106] and poorer post-discharge functional recovery [107] during hospital care than those without dementia.

Access to medical care, including admission to hospital and Intensive Care Units

Initial guidance from the regional Department of Health in Madrid [108], the epicentre of the pandemic in Spain, established that people living in care homes with moderate cognitive impairment (as per score in Global Deterioration Scale > 6) and suspect of COVID-19 should not be sent to hospital for care. This guidance was inspired by ICU protocols for triage in situations of catastrophe (for admission to ICU, not to hospital generally). This guidance was later amended after receiving criticisms from patient associations [109] and the regional Department of Social Affairs. Home care directors complained about ambulances not turning out to take very ill residents to hospital and having been left to deal with the outbreak on their own and without resources [110].

Guidance regarding triage for admission specifically to ICU affecting people with dementia have excluded anybody with dementia, irrespective of their usual level of wellbeing, independence and functional status. The guidance issued by the Spanish Society of Intensive Care [111], establishing criteria for admission to ICU, literally stated “any patient with cognitive impairment, either due to dementia or any other degenerative condition, will not be eligible to receive mechanical ventilation”. This protocol does not specify the level of cognitive impairment and in principle it denies mechanical ventilation to all people living with cognitive difficulties regardless the level of severity (e.g. people with mild Alzheimer’s disease, who may have more than a decade of life expectancy ahead of them). It is impossible to say how this guidance may have been implemented in practice and in response to level of overload in critical care units. There is however confirmation about the implementation of the ICU protocol used in IFEMA hospital in Madrid (the worst-hit COVID-19 region in country) that did guarantee access to ventilators to people living with dementia, excluding only those severe cases (the protocol specifies GDS ≥ 6) [112].

No information could be found regarding hospital admission for people with dementia living at home.

3.6.1. Measures to support people living with dementia

Measures to support people living with dementia in hospital and end of life care

Visits to hospitals or care homes to relatives infected with COVID-19 were banned at the beginning of the pandemic due to lack of PPEs and high risk of infections. This prohibition did not make special considerations to people living with dementia. Recently, some regions such as Asturias [113], Murcia [114] and the region of Valencia [84], produced protocols to organise and regulate visits to people living in care homes who are at end of life. Regarding visits to

hospitals, the media informed that some of them might be developing visiting guides according to which people with dementia could be visited by a relative some time over the course of hospital stay. However as per 18th of May date there is not public availability of those guidelines, or information regarding its implementation across the Spanish health system.

Therapeutic outings

Spain went into strict lockdown on the 14th March 2020 and citizens have been only allowed out to go to work, getting supplies or medicines. The Spanish Ministry of Health announced exceptions to this rule, one of them applying to people with mental health conditions or disabilities that may experience a worsening of symptoms due to confinement. People living with dementia fall within this exception and **are allowed out for 'therapeutic outings'** as long as there is written proof of this need (medical prescription or medical report indicating the diagnosis).

Support measures involving provision of information about confinement and COVID-19

Some institutions and professional societies, like the Spanish Neurology Society [115] have issued **advice and guidelines for families and people living with dementia** and some neurology departments launched new online resources to support their patients with dementia during the pandemic, for example the Hospital Universitario Central de Asturias[7]. Some municipalities also produced their own support guidelines [116] for families of people living with dementia and shared them through their institutional websites.

Many **local Alzheimer Associations** and charities have continued providing support [98] to family carers, mostly by phone or videoconference [100]and the National Alzheimer Association (CEAFA) has launched a section with support resources in their website[8]. The Fundación Matía[9] produces and shares on its website leaflets and infographics to support families of people living with dementia to respond to behaviours that challenge such as agitation, wandering and delusions.

Clinics through phone and videoconference

Neurologists and geriatricians across the country have **continued consultations over phone** or using telemedicine as common practice.

3.6.2. De-escalation

During phase 1 of the de-escalation process, that started in Spain on Monday 11th May, some regions [117] have given priority to the restoration of face to face activities in day care centres for people living with dementia (up to a maximum of 30% of the centre capacity) as long as restarting cognitive stimulation services. The solidarity funds from Globalcaja, a Castilla La Mancha's bank, made a donation to the regional Alzheimer's Association so that all local associations could be equipped with enough PPE to restart their services [104].

[7] http://www.neurologiahuca.org/unidades/demencias/
[8] https://www.ceafa.es/es/covid-19/recursos-alzheimer
[9] https://www.matiafundazioa.eus/es/documentacion-covid-19

4. Lessons learnt so far

4.1. Short and medium-term calls for action

- Infection prevention and control: from international experience we have learned that the best way to prevent COVID-19 infection in care homes is by preventing it from reaching in the home in the first place, which relies on controlling the spread of the virus in the community, or measures such as staff volunteering to live-in to shield residents from infection. However, once the virus enters a facility, a situation which has occurred in are homes throughout Spain, the most effective way to control its spread proved so far appears to be 1) blanket testing of staff and residents and 2) isolation of any positive cases. While the protocols now allow for blanket testing of staff and residents, with priority being given care homes where COVID-19 is present, testing in care homes has been slow to materialise, albeit with some notable exceptions. Given that much of the data that should have been made public has not yet been published it is not yet clear how far this has been achieved.

- Care homes also need to be provided with resources to isolate individuals affected and, if this is not feasible (for many care homes it is unrealistic to isolate residents since their spaces are designed for communal living), local governments and institutions should provide the means for isolation to happen (e.g. transferring infected individuals to quarantine centres or other purpose-designed facilities). Such measures are central to the evolved guidelines that are in place across Spain.

- In many areas in Spain, lack of official information on the situation in care homes is fueling anxieties. Given the complexities associated with confirming the true number of deaths from known or suspected COVID-19, the priority should be to release all available information on the current situation. Only two out of the seven items of information that the autonomous communities should be publishing relate to care home deaths (see table 3). The remainder, are figures relating to the current situation (number of residents currently infected; number of resident hospitalised, etc.) that need to be released in order to evaluate progress with flattening the curve in care homes.

- Adequate provision of personal protective equipment and efforts to hire and train new staff in their use are essential. The overall picture obtained during the production of this report, suggests that efforts must still be intensified. Again, greater transparency would increase trust and ensure that efforts can be targeted to where they are still required. Best practice examples have shown that the third sector can be an important source of practical support but this requires collaboration that requires knowledge of current gaps.

- Staff in care homes have taken on unprecedented levels of responsibility and had to work in physically and psychologically draining scenarios. The provision of psychological support does not appear to be widely available and must be prioritised. Also, financial compensation for the extra demands placed on staff (as has been employed in other countries) would help to boost morale.

- COVID-19 has disproportionately impacted users of long-term care services, and especially care home residents. There are four types of factors which might explain this impact: a) the *case-mix* of care homes and the level of the spread of COVID-19 in the area where the care home is located; b) the structural factors that define the care home (size and architectural design; training, labour conditions and number of staff; private or public ownership; funding model…); c) the response of each centre when it came to preventing and treating the virus and capacity issues; and d) the support that care homes have been provided where needed, including timely provision of PPE and access to testing. It is essential to carry out a nationwide assessment in order to evaluate the measures that have been taken and clearly establish which factors have had the largest impact in the spread of the virus.

- In the short term, clarifying the type of healthcare that care home residents should receive is urgent: when they should be admitted to hospital and when and how they should be cared for in the care home. People who become ill in a residential centre have a right to public healthcare, both general and specialized, as a result of their status as citizens. That they should have this right violated because of their age or disability status is inadmissible [118]. The rights of people with long-term care needs to access intensive care (ICU) need to be clarified and even regulated and guaranteeing that no discrimination would take place on the basis of age, long-term care needs, dementia diagnosis or other issues. Providing better health services in care homes is one of the major needs of the Spanish residential long-term care model, without necessarily converting care homes into medical centres [118].

- Ensuring continuity of support for people living with dementia is crucial to provide compassionate care in COVID-19 times. Partners in care can be enabled to accompany their relatives or friends with dementia in hospitals and care homes by implementing appropriate infection control protocols and use of PPE. The use of technology to support video calls with friends and family when a person with dementia is isolated should be encouraged.

4.2. Longer term policy implications

- The Spanish long-term care system lacks an adequate information management system and, more broadly, a shared innovation, evaluation and knowledge management model [73]. The COVID-19 crisis has highlighted the need for strengthening the current knowledge management and research and development efforts. For this, it is necessary

to combine the central administration's leadership with the local and regional administrations' activity, aided by the impulse of the Territorial Board for Long-Term Care, and the creation of other inter-administrative cooperation forums. The development of an agenda for knowledge management in the field of Social Services only makes sense if it is assumed as the regional administrations' own responsibility, although technical, political and economic support from central government will be essential [119].

- In this context, there is also a pressing need for the development of a shared quality indicator system, not only based on structure and process indicators, but, mainly, on outcome indicators related to the quality of life. This will allow for the transition from a model that is exclusively based on the regulation and inspection of the processes to a model which is more oriented towards the impact of the care process on the users' wellbeing and quality of life [9].

- The COVID-19 crisis has highlighted the Spanish long-term care system's shortcomings [120] and the need to develop a more community-based, more individualized and more person-centred model to achieving the best possible quality of life for people with long-term care needs and their families [17]. In this context, there is a need for a change in the long-term residential care model, so that older or disabled people can continue pursuing their life projects. It is vital that residential care centres provide attention which is centred on people, instead of viewing residents as objects to be taken care of. It is also necessary to evolve towards new architectural designs and organizational patterns which allow for personalized attention and smaller sized units [118].

- As has been stated earlier, the main shortcoming of residential centres is not just related to their economic resources but to their general orientation [17]. However, the question of economic resources is essential: a good quality long-term care system is costly, and there are a few Spanish regions which pay care homes below the rate it costs to provide care even at existing staff: resident ratios. The debate on the quality of residential care cannot be separated from the debate on the funding of the long-term care system [13].

- The COVID-19 crisis has also brought to the surface systemic problems in relation to human resource management. Professional profiles are poorly developed in terms of competences and training, and working conditions are less than ideal. In contrast with the health care system's response to COVID19, there has been a clear lack of leadership in the response to the crisis. The logic of the existing care home and home care models respond more to organisational convenience than to person-centred care [120]. In this sense, professionalism within long-term care is weak and the labour conditions in care homes are often poor. This was already well known, but had not been considered a social (or political) priority. While this is not the only problem that needs to be solved in order to guarantee good quality care, it is a question that must seriously be considered [118].

- The care home sector is increasingly dominated by private for profit providers, and there are longstanding concerns about decreasing quality standards as a result of efforts to contain costs in order to generate expected profit margins. The same issues are faced by public sector facilities that are managed by private providers. These factors may be behind the lack of preparedness to face a pandemic, which shows that most care homes are lacking infection control protocols, contingency planning for staff absences and the ability to procure personal protection equipment [120]. The private management model of public services undoubtedly requires strengthening the inspection and evaluation capacities of public administrations, as well as changes in contracting-out policies.

- The governance of the Spanish long-term care system involves all three levels of government (central, regional and local), which makes the system very unwieldy. This complicated governance makes it very difficult to adopt and implement ambitious measures and it has created legal difficulties in relation to, for example, purchasing equipment and re-organizing the workforce in response to the pandemic [70]. The COVID-19 crisis should prompt the revision of the institutional and territorial framework of the social services system in Spain.

- Provision of post-diagnosis support for people living with dementia is almost non-existent in the public health and care system in Spain and, when provided, it relies mostly on the good will of healthcare professionals and third sector organisations. Post-diagnosis support entails information, education, advice and training to live well with the condition (both for the person and the family) and other specialised support when needed such as access to psychological or speech and language therapies. Post-diagnostic support teams, if they had been in place, might have played a major advisory role supporting people living with dementia and their families to adjust to the challenges imposed by the confinement and the disruption of other support services.

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