

Preventing and managing COVID-19 across long-term care services

Policy brief

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Executive summary

The COVID-19 pandemic has affected older people disproportionately, especially those living in long-term care facilities. In many countries, evidence shows that more than 40% of COVID-19 related deaths have been linked to long-term care facilities, with figures being as high as 80% in some high-income countries. Furthermore, in long-term care facilities, the case fatality for residents with COVID-19 may be higher than in the population of the same age living outside long-term care facilities. Residents of long-term care facilities often face high risk, low preventive measures and inadequate resources to recover from COVID-19, as well as reduced access to essential health services in a context where health systems are experiencing constraints during the COVID-19 surge.

The impact of COVID-19 has additionally been high in providers of long-term care services, within long-term facilities and in other settings. A 2020 study by the United Kingdom Office for National Statistics of deaths by occupation found that the social care workforce had a significantly raised death rate associated with COVID-19.

So far, COVID-19 has disproportionately affected long-term care facilities. However, concerted action is needed to mitigate the impact across all aspects of long-term care, including home- and community-based care, given that most users and providers of care are those who are vulnerable to severe COVID-19. The response actions for long-term care will be one of the fundamental and essential steps in mitigating the COVID-19 pandemic in many countries. Only by addressing long-term care will countries be able to truly leave no one behind in the response to COVID-19.

This policy brief provides 11 policy objectives and key action points to prevent and manage COVID-19 across long-term care. Its intended audience is policy-makers and authorities (national, subnational and local) involved in the COVID-19 pandemic. The brief builds on currently available evidence on the measures taken to prevent, prepare for and respond to the COVID-19 pandemic and to mitigate impact across long-term care services, including care providers.

While this document contains policy options and actions relevant to all long-term care settings, long-term care facilities are emphasized because they have experienced extremely high COVID-19 incidence, morbidity and mortality.

Furthermore, the policy brief addresses long-standing problems in long-term care systems, including underfunding, lack of accountability, fragmentation between health and long-term care and an undervalued workforce. The brief suggests ways to transform health and long-term care services so that long-term care services are readily integrated and provided as part of the continuum of care that includes health promotion, prevention, treatment, rehabilitation and palliation. It is only through these measures that people in need of long-term care can receive quality, equitable and sustainable care that allows them to live in a manner respecting their basic rights, fundamental freedoms and human dignity.



Part 1. Overview

1.1 Aim of the document

The COVID-19 pandemic has revealed weaknesses in emergency response where long-term care services has been underprioritized, resulting in the devastating impact seen across long-term care services globally. These events have highlighted long-standing problems in the long-term care systems in most countries: underfunding, lack of accountability, fragmentation, poor coordination between health and long-term care, and an undervalued workforce (1–3).

This policy brief provides policy objectives and key action points to prevent and manage COVID-19 across long-term care for policy-makers and authorities (national, subnational and local) involved in the COVID-19 pandemic. The brief builds on current available evidence on the measures taken to prevent, prepare for and respond to the COVID-19 pandemic and its impact on those who use long-term care and care providers (including paid staff and family and other voluntary caregivers). It also expands on the technical working guidance on preventing and managing the COVID-19 pandemic across long-term care services in the World Health Organization (WHO) European Region to provide global perspectives and country examples across all WHO regions (4).

While this document contains policy options and actions relevant to all long-term care settings, long-term care facilities are emphasized as they have experienced extremely high incidence, morbidity and mortality due to COVID-19.

However, although long-term care facilities are an integral part of long-term care, it must be highlighted that community-based services are the key to promoting ageing in place, reducing institutionalization, and supporting deinstitutionalization, so that people can live in a manner consistent with their basic rights, fundamental freedoms and human dignity.

Box 1 presents definitions of the terminology used in this document.

Box 1. Working terminology: definitions of terms used

Long-term care systems

National systems that ensure integrated long-term care that is appropriate, affordable, accessible and upholds the rights of people and caregivers alike (1).

Long-term care

Services to ensure that people with or at risk of significant loss of physical and mental capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity (1). These services typically involve care and assistance with everyday tasks (including dressing, bathing, shopping, cooking and cleaning), support with social participation, and management of advanced chronic conditions through community nursing, rehabilitation and end-of-life care. Services are provided by both unpaid caregivers (typically family but also volunteers) and paid care staff.

Throughout the document, the use of the term “long-term care services” covers care at home, in the community and in facilities (residential long-term care facilities, nursing homes or other group living facilities), unless otherwise specified.

Long-term care facilities

Long-term care facilities may vary by country. Nursing homes, skilled nursing facilities, assisted living facilities, residential facilities and residential long-term care facilities are collectively known as long-term care facilities that provide a variety of services, including medical and assistive care, to people who are unable to live independently in the community. Throughout the document, the use of the term “long-term care facilities” does not include home-based long-term care, community centres, adult day care facilities or respite care.

Caregiver

A person who provides care and support to someone else. Caregivers may include family members, friends, neighbours, volunteers, care workers and health professionals (1).

1.2 Impact of COVID-19 on long-term care: what the evidence tells us

Evidence from a systematic review (5) and compiled reports on the COVID-19 situation in long-term care facilities (Annex 1) shows that, while there is little evidence of the impact of COVID-19 on people who use and provide long-term care services in the community, the pandemic has had a disproportionate effect on people, especially older people, who live in long-term care facilities. In countries with large numbers of deaths from COVID-19, about half of all those deaths have been among residents of long-term care facilities. The methods for the systematic review and other reviewing carried out for this report are described in more detail in Annex 1.

Early evidence shows that the extent of COVID-19 infections in long-term care facilities has varied widely, between and within countries: some countries (such as Jordan) have had no infections reported in long-term care facilities so far, whereas in Sweden, for example, by the end of April, 25% of long-term care facilities in the whole country had COVID-19 outbreaks, with 67% of long-term care facilities in Stockholm affected.

Data from 21 high-income countries show that while some countries have had no or very few deaths among residents in long-term care facilities, other countries report that on average nearly half of all deaths linked to COVID-19 in the country were of long-term care facility residents (ranging from 24% in Hungary to as high as 82% in Canada). In some countries, the share of deaths among all residents of long-term care facilities linked to COVID-19 has been as high as 3% to 6% of all residents (6). Disaggregated data by age and gender are not available for many countries.

“The pandemic has had a disproportionate effect on people, especially older people, who live in long-term care facilities.”

The evidence also shows that once COVID-19 infection is present in long-term care facilities it is difficult to control, in part due to the large number of people living close together in facilities designed for communal living and the fact that personal care requires close proximity. Although case reports from the Republic of Korea, demonstrated successful mitigation of further infections in long-term care facilities after a member of staff had tested positive (7–8), case studies in several other countries demonstrate how difficult it is to contain the infection in these settings. For example, studies in the United Kingdom of Great Britain and Northern Ireland and the United States of America have shown incidence rates between 40% and 72% among residents (9–14), with infection rates among staff between 1.5% and 5.9% when all staff members at outbreak facilities were tested (7–8, 15–18). There is also evidence from one study that staff working across more than one home may have been the source of transmission (19).

An analysis of deaths by occupation in the United Kingdom showed that men and women working in social care had significantly raised rates of deaths involving COVID-19 (23.4 per 100 000 males compared to 9.9 for males aged 20–64 years, and 9.6 per 100 000 females compared to 5.2 for females aged 20–64 years) (20).

Six studies describing measures to prevent (China and Singapore) and contain or manage (Canada and the Republic of Korea) outbreaks in long-term care facilities reported some success, although these studies did not have a control group (7–8, 22–23).

“Men and women working in social care have significantly raised rates of deaths involving COVID-19.”

There is increasing evidence of potential transmission from presymptomatic or asymptomatic people who have COVID-19 and people presenting with “atypical symptoms” in long-term care facilities. Studies of outbreaks show that 7% to 75% of residents and 50% to 100% of staff who tested positive are presymptomatic or asymptomatic (11–13, 15, 17, 19, 24). Between 57% and 89% of asymptomatic positive residents develop symptoms later (11, 19). Systematic nationwide testing of residents and staff in Belgium showed that 74% of cases among residents and 76% of cases among staff were asymptomatic at the time of testing (25).

Once people living in long-term care facilities have COVID-19, the case fatality for residents may be higher than in the population of the same age outside long-term care facilities. For example, the incidence rate of COVID-19 deaths among residents of long-term care facilities in Ontario, Canada, was 13 times higher compared to community-dwelling cases aged 70 years or older (26), and the risk for severe disease, including death, was 2.5 times higher for Israeli nursing home residents with COVID-19 compared to other cases over 65 years of age (27).

No studies report on the detrimental health sequelae of either the infection itself or the measures taken to prevent infection in long-term care facilities, although many editorials and commentary articles mention potential impacts on both mental and physical health (for example, distress, depression, anorexia, loss of physical condition due to lack of exercise, and consequences of increased chemical and physical restraints). This has raised concerns for increased direct and indirect morbidity and mortality (28–29).

There is limited evidence on the impact of the COVID-19 pandemic on people who use and provide community-based long-term care, including home help, day care facilities and unpaid caregivers. Some public health and infection prevention measures (including movement restrictions, physical distancing and curfews) may resulted in restriction of the usual sources of care and support that many people with care needs rely on. Evidence from the United Kingdom found that people with disabilities experienced widening inequalities during the COVID-19 pandemic. People with disabilities reported difficulty in accessing food and medication and delays in the benefit system, with some experiencing food insecurity and poverty. Many people with disabilities reported feeling isolated and, for some, lack of Internet access meant that they could not access virtual replacement services. Furthermore, reduction of ongoing support structures left people reliant on family and neighbours (30).

It is also likely that people living with existing health conditions experience difficulties in accessing essential health care services, including rehabilitation, which further increases care needs. Furthermore, discontinuity of health care services can result in heightened need for care (31–32).

It is increasingly recognized that in many countries the initial plans to contain the pandemic did not include long-term care facilities; it was only when media reports of large numbers of deaths started to emerge that resources were mobilized. In some countries, the army and other emergency response units had to be deployed to support long-term care facilities that had been overwhelmed by large numbers of deaths and insufficient staff (33). In many countries, long-term care facilities were only able to access testing, personal protective equipment (PPE) and medical support after large outbreaks in long-term care facilities had occurred (34).

“In many countries, long-term care facilities were only able to access testing, personal protective equipment (PPE) and medical support after large outbreaks in long-term care facilities had occurred.”

1.3 The case for action: leaving no one behind

Health systems have a responsibility to offer safe, accessible, affordable and quality health care, including assistive and palliative care, for all people, without discrimination.

However, as the evidence shows, residents of long-term care facilities are often facing higher risk, lower preventive measures and inadequate resources to manage COVID-19, as well as reduced access to essential health services, as health systems experience constraints in the context of a COVID-19 surge (35).

Older people, particularly those with underlying conditions who are more likely to develop severe COVID-19, make up a large proportion of those using long-term care services, including those living in long-term care facilities (36). Immediate action is required to prevent infection and mitigate the impact of the COVID-19 pandemic among this population and to ensure that essential health and assistive care services are provided.

Furthermore, women, especially older women, represent the highest share of people who use care services, dominate the long-term care workforce, and are the main providers of family care (1, 37). In addition, long-term care services often depend heavily on migrant workers and workers from ethnic groups, who may be at higher risk (1, 38–40).

The response to the pandemic must include long-term care to ensure that ethnic, age and gender groups are not marginalized.

Concerns about human rights have also been expressed, both in the potential neglect of the population relying on (and providing) long-term care, and in measures adopted in an attempt to reduce the risk of infection (for example, a ban on visitation and forbidding outside physical activity). It is mandatory that the response to the pandemic is inclusive of long-term care, so that appropriate and tailored measures are implemented and issues specific to long-term care are addressed.

So far, COVID-19 has disproportionately affected people living in long-term care facilities. However, concerted action is needed to mitigate the impact across all aspects of long-term care, including home- and community-based care, given that most users and providers of care are those who are vulnerable to severe COVID-19.

Considering the magnitude of the impact of COVID-19 on long-term care, response actions for long-term care will be one of the fundamental and essential steps in mitigating the COVID-19 pandemic in many countries (4).

Only by addressing long-term care will countries be able to truly leave no one behind in the response to COVID-19 (41).



UNSPLASH / AP X 90

Part 2. Responding to the COVID-19 pandemic in long-term care

While the pandemic has brought public attention to the immediate impacts of the pandemic, and the need to be prepared for present contingencies and possible future waves, it has also shown that there are major structural challenges that need to be addressed to improve the safety and resilience of long-term care systems.

So far, most countries have struggled to develop coherent systems to ensure access to person-centred, quality, long-term care services that meet the growing health and assistive care needs and that are consistent with basic rights, fundamental freedoms and human dignity (1, 42–45). Even in high-income countries, a review by the Organisation for Economic Co-operation and Development (OECD) concluded that “there is a history in many countries of long-term care policies being developed in a piecemeal manner, responding to immediate political or financial problems, rather than being constructed in a sustainable, transparent manner” (43).

This section looks into the unique challenges that have affected the ability of long-term care systems to respond to the COVID-19 pandemic and proposes policy objectives and key actions to address these challenges in the short and longer term.

Informed by the available evidence and international experience thus far, the 11 policy objectives presented on the next page will be key to addressing COVID-19 in long-term care systems.

The following subsections address each of these policy objectives in turn.

Eleven policy objectives to mitigate the impact of COVID-19 across long-term care



1. Include long-term care in all phases of the national response to the COVID-19 pandemic.
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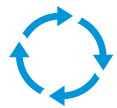
2. Mobilize adequate funding for long-term care to respond to and recover from the COVID-19 pandemic.
-



3. Ensure effective monitoring and evaluation of the impact of COVID-19 on long-term care and ensure efficient information channelling between health and long-term care systems to optimize responses.
-



4. Secure staff and resources, including adequate health workforce and health products, to respond to the COVID-19 pandemic and deliver quality long-term care services.
-



5. Ensure the continuum and continuity of essential services for people receiving long-term care, including promotion, prevention, treatment, rehabilitation and palliation.
-



6. Ensure that infection prevention and control standards are implemented and adhered to in all long-term care settings to prevent and safely manage COVID-19 cases.
-



7. Prioritize testing, contact tracing and monitoring of the spread of COVID-19 among people receiving and providing long-term care services.
-



8. Provide support for family and voluntary caregivers.
-



9. Prioritize the psychosocial well-being of people receiving and providing long-term care services.
-



10. Ensure a smooth transition to the recovery phase.
-



11. Initiate steps for transformation of health and long-term care systems to appropriately integrate and ensure continuous, effective governance of long-term care services.
-

2.1 INCLUDE LONG-TERM CARE IN ALL PHASES OF THE NATIONAL RESPONSE TO THE COVID-19 PANDEMIC

2.1.1 The challenge

Long-term care has low political priority compared to health and other policy areas

Long-term care tends to have low political priority and is often referred to as “the Cinderella of the welfare state”, where political attention to its importance is often transient and secondary to health care (46). This lack of political attention to long-term care may be one of the reasons why the initial policy responses to the pandemic in many countries did not include the long-term care sector (4).

Governance of the long-term care system often involves multiple sectors, different ministries and different levels of government, making coordination difficult

In most countries, long-term care falls between different ministries, typically health care and social affairs, development, or social protection. Long-term care services and health care systems are often poorly coordinated or integrated, and tend to have separate (and often complex) arrangements for financing, regulation, information systems, and the training and procurement of staff (1, 43).

This has created several difficulties during the COVID-19 crisis. For example, back-up staffing models to meet the surge in COVID-19 patients in hospitals were not flexible enough to meet demand surges in the long-term care sector. It was also difficult for appropriate staff to move flexibly across the system as needed. Similarly, the long-term care sector, and especially long-term care facilities, struggled to access testing and PPE, as this had been prioritized for hospitals (47).

In addition, countries frequently distribute responsibility for long-term care vertically across national, regional and local actors, creating difficulties in coordination of services and effective oversight (48). For example, in Spain and Italy, the same person may be receiving long-term care services that are organized or funded by up to three different levels of government (49–50).

Long-term care services consist of a mixture of public, private for-profit and private not-for-profit service providers, in addition to family caregivers

Long-term care services are also characterized by a mix of public, private for-profit and private not-for-profit service providers (51). In some countries, most long-term care facilities are operated by private for-profit providers and, particularly in low- and middle-income countries, these are often unregulated (52–53).

Particularly in low- and middle-income countries, nongovernmental organizations (NGOs) play an important role in the provision of long-term care services and are often the sole source of support for unpaid caregivers. However, where NGOs are non-existent, the care responsibility often falls entirely on the families themselves. This unpaid care is rarely recognized within a formal system and so is not included in any governance processes or mechanisms beyond those of the NGOs that support the work. These structures can result in a lack of ownership, diffused accountability, and fragmentation of responsibilities, causing problems with coordination and quality of care and leading to underdeveloped information systems (43, 54).

IMPLICATIONS IN THE CONTEXT OF COVID-19

- ➔ May impede inclusion of long-term care in pandemic national response
- ➔ May impede planning, oversight and accountability during the pandemic
- ➔ May impede coordinated response between long-term care and health care sectors in responding to the pandemic
- ➔ May impede effective resource allocation

2.1.2 Key actions

Whole sector

- Ensure a focal point to manage long-term care (with a special focus on long-term care users and providers) in the overarching COVID-19 governing body.
- Establish joint steering committees and information- and data-sharing systems between sectors and subnational policy levels to ensure a coordinated response.
- Establish a mechanism to support unregulated providers, focusing on cooperative support rather than punitive measures.

Long-term care facilities

- If long-term care facilities are expanding their health care role during the pandemic, establish triggers or thresholds that activate a phased reallocation of routine comprehensive health service capacity, including direct health care staff.

Country examples

In **Singapore**, the Agency for Integrated Care and the Ministry of Health, together with long-term care service providers, have jointly developed a number of measures to respond to the COVID-19 pandemic. These include infection control and prevention measures, access to PPE, distancing and zoning measures, suspension of visitors, alternative accommodation for long-term care workers, and testing to monitor people with long-term care needs and care workers. The Agency for Integrated Care also set up an incident response team to support long-term care providers in responding to COVID-19 infections. The Silver Generation Office, which is an outreach arm of the Agency for Integrated Care, has supported older people with contact, information and the provision of services during the COVID-19 pandemic (55–56).

In **Israel**, a governing team has been appointed to manage COVID-19 outbreaks in long-term care facilities across the country. This team has provided a national plan under the Fathers and Mothers Shield project, including establishment of a headquarters from which government efforts can be coordinated. In addition, the Home Front Command has been assisting long-term care facilities throughout the pandemic with managing visitor access, disinfection, and food and equipment delivery, and has been offering training and guidance on protective and preventive measures (57).

In **Malta**, the Social Care Standards Authority, the regulatory body for long-term care, defined the residential care settings as being high risk with regard to COVID-19 in early March. Immediately, the Social Care Standards Authority issued the directives mapped out in its COVID-19 brief (2020). There was immediate cooperation between the Public Health Authority and the Social Care Standards Authority, which proved to be the primary catalyst towards safeguarding older persons within the facilities (58).

2.2 MOBILIZE ADEQUATE FUNDING FOR LONG-TERM CARE TO RESPOND TO AND RECOVER FROM THE COVID-19 PANDEMIC

2.2.1 The challenge

Limited public funding allocated for long-term care

Average public expenditure on long-term care is very low, less than 1% of GDP globally. Such public underfunding jeopardizes access to long-term care (42). This is even more pronounced in low- and middle-income countries, many of which lack dedicated sources of public financing for long-term care.

Public benefit schemes for long-term care are usually needs based and means tested, and often require co-payments, leaving large parts of the population outside the public system

In most countries, public benefit schemes for long-term care support are needs based and means tested, and often require co-payments. Those with greater needs often receive more support, but some countries also set limits on the amount that can be covered through public resources. While some countries protect the most vulnerable from additional costs, considerable out-of-pocket expenses are common across countries for most people receiving long-term care services (43, 59–60). Also, due to the large share of care provided by unpaid caregivers, in practice a large share of the costs of long-term care fall on families, through a combination of the opportunity costs of providing care and out-of-pocket payments. Few countries have financing mechanisms that protect the whole population from catastrophic long-term care costs (1).

Reduced income for long-term care sector and higher costs of care

Increasing PPE and workforce costs mean that service providers are facing substantial additional costs. At the same time, providers are experiencing decreases in revenues due to lower occupancy in long-term care facilities (resulting from both a decrease in admissions and the higher-than-usual numbers of deaths) and the closure of community-based services such as day care centres.

Several countries have already provided emergency funds to support the long-term care sector during this crisis. However, the provision and distribution of resources may be easier in countries with more developed and regulated long-term care systems. The provision of resources and support to the unregistered long-term care sector poses additional challenges.

Such unique challenges in the financing of long-term care have made it difficult for the long-term care system to react and respond to the additional costs that may be incurred due to preparing for and responding to COVID-19.

IMPLICATIONS IN THE CONTEXT OF COVID-19

- ➡ Lack of adequate funding for the additional costs linked to the COVID-19 response may endanger the safety of long-term care users and providers
- ➡ The increase in the costs of care due to the pandemic results in increased out-of-pocket payments for care users

2.2.2 Key actions

Whole sector

- Consider injecting extra ring-fenced funds for long-term care to cover the additional costs linked to the pandemic (for example, additional staff costs, infection prevention and control (IPC) training, and materials such as PPE and sanitizers).
- Consider how to reduce regulatory and other costs to providers for the duration of the pandemic (such as staffing requirements).
- Provide flexibility in the use of emergency funds allocated to long-term care providers as well as users.

Long-term care facilities

- Provide funding to compensate for lower occupancy rates and ensure provision of quality essential health and care services.
- Provide funding to support providers of long-term care facilities with the additional costs incurred in ensuring the safety of their residents and staff, including additional IPC measures and testing for COVID-19.

Community-based care

- Support providers (particularly not-for-profit) that are experiencing loss of revenue if they have to close some services, such as day care and community centres, during the pandemic.
- Enable flexibility in the use of personal budgets and other cash benefits, for example by allowing them to be used to employ a family member or neighbour if community centres are not available.

Caregivers

- Support caregivers who may need to take on additional care responsibilities to compensate for the unavailability of usual care, and may need to give up employment to do so.

Country examples

In the **United States**, the US\$ 3 trillion COVID-19 stimulus package (under the Coronavirus Aid, Relief, and Economic Security (CARES) Act) provides some funding for the long-term care sector. Out of the US\$ 100 billion funding allocated to health care providers under the CARES Act, US\$ 50 billion is being distributed to hospitals and long-term care providers, including providers of home health (61). As of 3 June 2020, US\$ 4.9 billion had been targeted to skilled nursing facilities (62).

In the **Republic of Korea**, the Ministry of Health and Welfare and the Korean National Health Insurance Service have issued temporary reimbursement guidelines for the long-term care sector. The guidelines take into consideration the need for COVID-19-related physical distancing measures and staff shortages. In addition, service providers operating in special disaster zones will not be facing payment cuts if they cannot adhere to staffing requirements during the pandemic (63).

In **China**, subsidized long-term care providers were allocated a special one-off allowance to support staffing (for example, hiring and redeploying workers and reimbursing overtime) to ensure the continued provision of long-term care services. It is estimated that this support will amount to a total of around US\$ 1.6 million (64–66).

2.3 ENSURE EFFECTIVE MONITORING AND EVALUATION OF THE IMPACT OF COVID-19 ON LONG-TERM CARE AND ENSURE EFFICIENT INFORMATION CHANNELLING BETWEEN HEALTH AND LONG-TERM CARE SYSTEMS TO OPTIMIZE RESPONSES

2.3.1 The challenge

Few countries have information and monitoring systems for long-term care systems

Relatively few countries have information and monitoring systems that include individual-level data about the characteristics, needs and outcomes of people who use formal long-term care services, and about the type and quality of care that they are receiving. This reflects the overall situation of limited data sources about older people (who are often long-term care users) and lack of age- and gender-disaggregated data (67).

Where individual-level data are available, quite often they only cover people who use publicly funded long-term care or provide services. Furthermore, health and social care data are usually collected under separate systems, leading to difficulties linking data for the same individual.

There are reports of unregulated long-term care facilities being “discovered” as a result of the COVID-19 pandemic (68). Lack of individual-level data about the characteristics of the residents of long-term care facilities has been identified as a barrier to response planning for the COVID-19 pandemic (69–70). This has meant, for example, that mathematical models that have informed planning for the pandemic have not accounted for residents in long-term care facilities separately from surrounding populations in their calculations (71).

Data on the pandemic were initially only collected on people who had been tested and died in hospitals

Very few countries publish data on the numbers of residents of long-term care facilities who have been infected or died from confirmed or suspected COVID-19. Because residents of long-term care facilities have been less likely to be tested or admitted to hospital than people living in private households, it is likely that countries that do not include deaths outside hospital are underestimating the death toll of COVID-19.

An international initiative to track data on deaths of residents of long-term care facilities only found publicly available data for 21 countries in May 2020 (6). Without data on the impact of the infection on long-term care facilities and on people who rely on care and live in the community, there is a risk that the resources needed to prevent and mitigate the impact of COVID-19 in the long-term care sector (funds, workforce, tests, PPE and other equipment) may not be provided adequately and in a timely manner.

There are few data available on associated health impacts of the pandemic

Many people who rely on assistive care, particularly community-based care, will have had disruptions in their usual access to care, which can potentially put them at risk (for example due to malnutrition, undetected infections or other health complications). Data to identify people who may be at higher risk are needed to identify gaps and reconfigure services as needed.

IMPLICATIONS IN THE CONTEXT OF COVID-19

- ➔ Difficult to monitor the impact of COVID-19 across long-term care services
- ➔ Difficult to develop tailored response plans for long-term care to mitigate impact
- ➔ Difficult to include long-term care populations in modelling projections
- ➔ Difficult to monitor health impact of COVID-19 on long-term care users and long-term care workforce
- ➔ Fragmentation of information between long-term care facilities and health facilities

2.3.2 Key actions

Whole sector

- ❑ Find effective ways to make use of existing long-term care management data where they are available (for example, MDS 3.0 in the United States, and the interRAI assessment systems of Canada and New Zealand) to model the impact of COVID-19 on health (including mental health) and the functioning of older people in long-term care. For countries without these systems, consider establishing such management data systems as actions for the longer term.
- ❑ Encourage research on the impact, and measures to mitigate the impact, of COVID-19 on long-term care to identify gaps and prepare for future pandemics.

Long-term care facilities

- ❑ Establish a surveillance system that captures people who have COVID-19 and deaths that occur in long-term care facilities (probable and confirmed, disaggregated by age, gender, disability and existing health condition), and ensure that these are integrated with existing surveillance systems.
- ❑ Establish the necessary legal mechanisms to secure and transmit information relating to COVID-19 on a regular and frequent basis to and from long-term care facilities, health facilities, public health authorities and the public.
- ❑ Set up a mechanism to ensure that these data are analysed regularly and the findings used to refine government policy on the COVID-19 response.

Community-based care

- ❑ Establish mechanisms to report the number of people who have COVID-19 among those receiving and providing long-term care in the community and in homes to public bodies responsible for commissioning services.

Examples

In **South Africa**, managers of long-term care facilities have to inform the Department of Social Development if a COVID-19 case has been confirmed (72).

In the **European Union**, the European Centre for Disease Prevention and Control (an agency of the European Union) has included long-term care facilities in its strategy for COVID-19 surveillance at national and European Union/European Economic Area levels and is collecting data from Member States covering mitigation action, infection rates and mortality (73).

In **Argentina**, in La Plata, an NGO co-developed a website for monitoring and sharing information about both registered and informal long-term care facilities. This platform was used to survey the COVID-19 preparation of the long-term care facilities and resulted in the local government ensuring that testing was provided to all employees of long-term care facilities (53).

2.4 SECURE STAFF AND RESOURCES, INCLUDING ADEQUATE HEALTH WORKFORCE AND HEALTH PRODUCTS, TO RESPOND TO THE COVID-19 PANDEMIC AND DELIVER QUALITY LONG-TERM CARE SERVICES

2.4.1 The challenge

Pre-existing workforce shortages, poor pay and working conditions

Before the COVID-19 pandemic, workforce shortages, poor pay and working conditions, and low proportions of professionally qualified staff were already a major concern in long-term care systems (2–3, 73). The workforce supporting people with long-term care needs is predominantly female (90%) (37), and in many countries migrant care workers make up a large proportion of the long-term care workforce (74). It is common for care workers to have zero-hour contracts and to work for multiple facilities or agencies (75).

Long-term care staff shortages during pandemic

In many countries, long-term care services, particularly long-term care facilities, have experienced acute staff shortages during the COVID-19 pandemic when their staff had to isolate due to suspected or confirmed infection with COVID-19 (49–50, 76–77). This has happened at a time when family and other unpaid caregivers, due to visiting and movement restrictions, have been less able to provide support (even in long-term care facilities, family and volunteer caregivers make an important care contribution). On some occasions countries had to rely on extreme measures such as calling on the military or other emergency services when long-term care facilities became overwhelmed and understaffed (49).

In some countries, long-term care workers and caregivers were not initially considered key workers and lockdown measures and curfews meant they were not able to travel to work (or continue to provide care to people in other households) (78–79). Using public transport or living in cramped accommodation may have increased the risk for care staff to be exposed to the virus.

Difficulties adapting to increased health care needs in long-term care facilities

While some long-term care facilities employ nurses and other health care staff, this is not the case in all facilities, and there are reports of the difficulties faced by non-medically trained staff in long-term care facilities needing to provide care to people with COVID-19 infections or to those who need palliative care without health care staff support or oversight by qualified health professionals such as physicians and nurses.

Administrative barriers to transferring staff and medical supplies from the health service to long-term care facilities led, in the case of a region of Spain, to all long-term care facilities being put under the control of the Department of Health during the pandemic (49).

Long-term care providers and caregivers not able to obtain PPE

Difficulties faced by long-term care providers and caregivers in accessing PPE and other resources (such as hand sanitizer and disinfectant) have emerged in many countries, due to global shortages and the prioritization of hospitals and other health care settings. Long-term care providers reported having to buy PPE at inflated prices as a result.

IMPLICATIONS IN THE CONTEXT OF COVID-19

- ➔ A vast workforce shortage for long-term care
- ➔ When compensating for workforce shortage, high staff turnover can impede continuity of care and consistency in important IPC measures
- ➔ Decreased integrity of the work and value of a workforce dominated by women and migrant workers
- ➔ Increased financial pressures to work while ill due to poor working conditions, such as lack of compensation for sick leave
- ➔ Occupational safety of long-term care workforce not taken into careful consideration
- ➔ Substantial lack of PPE for long-term care facilities, long-term care workforce (including caregivers) and recipients of care
- ➔ Lack of essential medical supplies and health workforce in long-term care facilities
- ➔ Lack oversight by qualified health professionals in providing essential services in long-term care facilities

2.4.2 Key actions

Whole sector

- Estimate surge capacity needed to support long-term care services in coordination with the focal point on long-term care.
- Set up links between health and social care procurement chains to ensure a continuous and non-conflicting supply during COVID-19.
- Recruit additional staff and develop rapid training programmes (for example, recruit retirees, students from health and long-term care training programmes, and volunteers) on IPC measures.
- Address contractual and related issues and put in place policies and measures that keep staff safe but allow them to work in a flexible manner and move from health care services into long-term care services as needed.
- Establish rosters and secure staff from health systems who can be repurposed if needed to support staff in long-term care settings.
- Implement measures to prevent policies from impeding delivery of important home, community and facility-delivered care through the long-term care workforce.
- Implement measures to monitor staff working in multiple locations, with increased risk of transmission, and consider facilitating transport and accommodation of staff to minimize the risk of infection during local outbreaks.
- Provide financial payment for care staff to incentivize them to stay in their jobs during the epidemic and compensate them for additional workload and stress.

Long-term care facilities

- Ensure adequate supply of PPE in long-term care facilities to protect care staff from infection.
- Provide adequate training guidance and enforce routine training of staff and family caregivers on IPC measures in long-term care facilities so they can continue providing care in those facilities.
- Facilitate flexible arrangements whereby palliative care teams and other relevant health and care professionals work with staff in long-term care facilities to ensure access to palliative care as needed.

- Ensure adequate oversight by appropriately trained personnel to deliver essential services in long-term care facilities.
- Ensure provision of PPE to home care workers, particularly those providing care in close proximity.
- Provide adequate training guidance and enforce routine training of community-based care providers.

Family and other voluntary caregivers

- Ensure provision of PPE to caregivers providing care in close proximity.
 - Provide adequate guidance and offer training for family and other voluntary caregivers.
-

Country examples

In **Austria**, staffing and licensing regulations for care workers have been eased substantially during the COVID-19 pandemic. This enables people who have done national service (those who opted for civilian duties) to provide basic care. People in the national service have contributed to managing the logistics of the pandemic. Their employment as care workers can be enforced by the government. In addition, people undertaking training in relevant areas and interested people who are currently unemployed can also step in (76).

In **Ireland**, Nursing Homes Ireland started a recruitment campaign for nursing homes (private and NGO operated) in March 2020. Furthermore, the Health Service Executive agreed to redeploy staff (on a voluntary basis) to private nursing homes (77).

In **India**, some long-term care facilities support their in-house staff with incentives, such as free food. In addition, some long-term care facilities are working to promote the mental health of their staff through regular check-ins and counselling (78).

If long-term care facilities in **Israel** experience a shortage of staff, the Ministry of Health will send a special team for 7–14 days to support the provision of care for the acute period (57).

In the **Netherlands**, since 19 May 2020 PPE has been available free of charge for care workers providing care activities that require close proximity (less than 1.5 metres) to persons with long-term care needs (80).

In **Spain**, care staff from community care centres have been supporting the provision of home care, for example through phone calls. In addition, the long-term care sector can hire non-qualified staff in instances of absenteeism of their usual staff (49).

In **Australia**, residential care workers will receive a retention bonus for two quarters of up to 800 Australian dollars after tax. The government has employed health care delivery providers to form rapid response teams in the long-term care sector where needed in each state. Visa rules were relaxed to enable staff to work more hours (81).

In parts of the **United Kingdom**, care workers have had their wages increased and have been offered a special one-off payment for staff working during the COVID-19 pandemic (82).

2.5 ENSURE THE CONTINUUM AND CONTINUITY OF ESSENTIAL SERVICES FOR PEOPLE RECEIVING LONG-TERM CARE, INCLUDING PROMOTION, PREVENTION, TREATMENT, REHABILITATION AND PALLIATION

2.5.1 The challenge

Requirement for continuous, complex care with high levels of physical and emotional contact

People with long-term care needs often require continuous, complex and personalized support structures. Assistive care for personal tasks in particular requires high levels of physical and emotional contact. People who are receiving this care, and who are dependent on this support, benefit enormously from continuity of care (1). In many countries, the majority of residents of long-term care facilities have dementia (83–85).

Variability in health care provision in long-term care facilities

Long-term care facilities are very diverse, and while some may be specialized in providing medical care, such as long-term care hospitals or some nursing facilities, others, typically residential homes or supported accommodation, may not have any health care trained staff members. Long-term care facilities in many countries have experienced difficulties providing health care support and resources for essential health services, in addition to responding to the new burden of COVID-19 (including in the areas of rehabilitative and palliative care).

Potential for discriminatory triage practices in hospital admissions

There have been reports that residents of long-term care facilities have not been able to access health care in hospitals (49–50), and have had limited access to primary care. It has also been reported that advance care directives have sometimes been put in place without adhering to the usual person-centred standards (86). Countries have responded by emphasizing the importance of equitable access to health and palliative care for older adults and people with existing conditions during the COVID-19 pandemic (36–37).

IMPLICATIONS IN THE CONTEXT OF COVID-19

- ➡ Long-term care facilities in many countries have experienced difficulties providing health care support and resources to continue essential health services and to provide assistive care services for the new challenge of COVID-19
- ➡ Residents of long-term care facilities have sometimes been denied hospital care based on irrelevant or discriminatory criteria, such as age, under the presumption that they are too frail to survive

2.5.2 Key actions

Whole sector

- Consider developing clear COVID-19 care pathways, inclusive of long-term care facilities and home- and community-based care, for transfers to primary, secondary and tertiary care for people with COVID-19 and non-COVID-19 symptoms (87–89).
- Consider appropriate tele-health and virtual technologies for consultations, taking account of the views of older people, and provide any support necessary to use this technology effectively.
- Ensure that all palliative care plans and advanced care directives are up to date and applied through a person-centred approach.
- Ensure that national and regional policies, programmes and guidelines are in place to support the provision of palliative care in long-term care facilities and long-term care services (including physical, psychological, social and spiritual support).

Long-term care facilities

- Consider involving the residents of long-term care facilities in the development of protocols for referral and access to essential health services. Ensure there is no selection based on age or disease in such protocols, but that people's needs and preferences determine care decisions.
- Ensure that all long-term care facilities are supported by a primary care service.
- Establish rapid response teams, preferably with geriatric and palliative care training, for long-term care facilities for older people, to reduce avoidable hospitalizations and ensure optimal person-centred communication and decision-making.
- Ensure that staff are trained in providing palliative care and know how to communicate about death, dying and end-of-life decisions (35).

Country examples

In the **United States**, the use of home-based tele-health has been expanded as remote patient monitoring can now be reimbursed. Since March 2020, Medicare beneficiaries have been able to receive behavioural or substance use disorder interventions. For people with severe symptoms of COVID-19, post-acute tele-health visits are now possible. This enables social workers, clinical psychologists, physical therapists, occupational therapists and speech-language pathologists to perform remote evaluations and therapy. This may also support people with long-term care needs living in the community (61).

In **Italy**, special palliative care teams were able to reorganize themselves rapidly in order to respond to demand quickly and flexibly. For example, they created networks of hospice care services by shifting staff from hospice inpatient to home care services. The experiences also highlighted the important need for case conferences and similar team collaborations to be able to decide quickly where to prioritize resources (for example, by deciding who will get support after hospital discharge) (50, 90).

In **Austria**, the National Association for Palliative Care has issued a position paper on palliative care during the COVID-19 pandemic and has provided guidance on ensuring access to palliative care for people who will not receive the intensive care that normally is provided. The association has also published guidelines for family caregivers and long-term care workers. Furthermore, multidisciplinary guidance provided by the government is available to support people with COVID-19 who are reaching the end of life. There are also clinical guidelines and resources on how to facilitate social support and on bereavement for family carers and care workers supporting a person who reaches the end of life during the COVID-19 pandemic (76).

In **Slovenia**, medical teams are ready to be sent to residential long-term care facilities to support regular staff if they become exhausted or overwhelmed (91).

2.6 ENSURE THAT INFECTION PREVENTION AND CONTROL STANDARDS ARE IMPLEMENTED AND ADHERED TO IN ALL LONG-TERM CARE SETTINGS TO PREVENT AND SAFELY MANAGE COVID-19 CASES

2.6.1 The challenge

Lack of mandatory implementation of IPC guidance for long-term care

Guidance on IPC for long-term care providers has been developed relatively late in the pandemic in many countries, and many of the guidelines have been slow to incorporate evidence of asymptomatic transmission and atypical symptoms of COVID-19. In many countries, guidance has only been developed for long-term care facilities, with no guidance available for providers of community-based care and for family caregivers. Finally, there is a lack of mechanisms to ensure implementation of these guidelines and to monitor their implementation.

Lack of IPC experience and training in long-term care and resultant implementation difficulties

In many countries, long-term care providers have weak IPC systems and training in place, resulting in many staff being unfamiliar with IPC and the correct use of PPE.

This is a particular challenge for long-term care facilities that make high use of temporary or agency staff. Even where guidance and training are available, implementing some of the measures can be challenging due to the need for personal assistive care to be provided in close proximity. Lack of availability of testing and PPE, shortages of staff, difficulties in implementing physical distancing (given the design of traditional long-term care facilities), and a lack of alternative isolation facilities have been reported in countries that have struggled to contain infections in long-term care facilities.

Across countries, guidelines have identified the importance of isolating residents exhibiting COVID-19-related symptoms, as well as those who have been in contact with people who are suspected of having or confirmed to have COVID-19. While in some countries residents in long-term care facilities live in single rooms with their own wet rooms, this is not the case in others. The specific structure of buildings in which long-term care facilities are housed may also pose barriers to the establishment of effective quarantine zones. Managers of long-term care facilities need to be supported in assessing the capacity of facilities to enable effective isolation policies and to provide additional quarantine spaces should the care setting not lend itself to effective isolation strategies.

Countries that had experienced severe acute respiratory syndrome and Middle East respiratory syndrome had recently strengthened their IPC systems in long-term care facilities and community-based settings and have tended to systematically transfer people who are suspected or confirmed to have COVID-19 to isolation facilities, which appears to have been successful in controlling outbreaks (63). However, evidence on the impact of these measures on the mental and physical well-being of residents is not yet available.

In some countries, there are large numbers of unregistered and therefore unregulated long-term care facilities. It is essential to support these facilities to ensure that they can keep their residents safe (53).

Similarly, community-based care services are less often subject to direct regulatory control than residential long-term care facilities, and there are even fewer well developed information and monitoring systems that would enable the gathering of timely information on how the pandemic is affecting, directly or indirectly, people who rely on community-based care. Home care providers typically visit people with care

needs in their own home. This means that care workers need to travel between homes and often visit multiple people with care needs. There is evidence that families have stopped using home care support to reduce the risk of infection for the person with care needs; however, this may create other risks (77, 81).

IMPLICATIONS IN THE CONTEXT OF COVID-19

- ➔ Lack of mechanisms to ensure implementation of IPC guidelines and monitor and assess implementation
- ➔ Lack of training of long-term care workforce on IPC measures
- ➔ High staff turnover impedes continuity of care and consistency of IPC measures
- ➔ Physical distancing is difficult to achieve for long-term care services
- ➔ Care workers cannot adequately access information on limiting transmission in the context of COVID-19

2.6.2 Key actions

Whole sector

- ❑ Establish a coordinating body to develop, adjust and update IPC guidance and protocols during the COVID-19 pandemic for long-term care, based on the best available evidence (87-88, 92-93).
- ❑ Ensure implementation of the IPC guidance across long-term care services (for all settings).
- ❑ Establish a mechanism to plan, prioritize support for, and monitor implementation of measures to protect staff and people receiving long-term care from infection or spread of COVID-19.
- ❑ Establish early recognition, surveillance thresholds and escalation strategies for outbreaks of COVID-19 across long-term care.
- ❑ Consider how to ensure that providers of long-term care who may be operating outside the system (unregulated or illegal providers) can be supported to ensure the safety of the people living in their facilities or using their services.
- ❑ Ensure that everyone involved in direct delivery of care (staff and family caregivers), in long-term care facilities or in home care services, has access to IPC training (including use of PPE, hand hygiene, cleaning and disinfection of environments and waste management). This should be carried out regardless of their role, and especially for those having direct contact with older people with underlying health conditions (93).
- ❑ Consider developing and circulating standard operating procedures that give direction on how and when to rapidly isolate people receiving long-term care services, using the most up-to-date COVID-19 guidance.
- ❑ Implement extended IPC precautions for people discharged from hospital, based ideally on an agreed protocol for testing to determine individual needs for isolation and PPE required.
- ❑ Translate any strategies for standard operating procedures into clear referral systems that are made available to all staff delivering long-term care services.

Long-term care facilities

- ❑ Ensure implementation of IPC guidance in long-term care facilities with reference to the WHO IPC guidance for long-term care facilities in the context of COVID-19 (92).
- ❑ Implement administrative controls, including syndromic surveillance upon entrance to a facility, for all staff and visitors.

- Ensure that staff in long-term care facilities have working conditions and arrangements that minimize their movement between settings and people receiving long-term care services, and that sick pay enables them to stay at home if they are unwell.
- Ensure that long-term care facilities have access to the resources needed to implement IPC (such as PPE, hand sanitizers and disinfectant).
- Develop the necessary IPC protocols and guidance and ensure that they are made available for visitors and are clearly visible in easy-to-understand formats (94).
- Develop guidance and ensure implementation of IPC protocol for staff and ensure educational resources are provided alongside continuous training.
- Ensure that long-term care facilities have an IPC focal point to lead and coordinate IPC activities, ideally supported by an IPC team with delegated responsibilities and advised by a multidisciplinary committee.

Community-based care and caregivers

- Increase training and decision-making support for the long-term care workforce in the community to effectively manage COVID-19, including family caregivers, keeping in mind constraints, especially gender-related constraints, that family caregivers may face (87–88).

Country examples

In **Jamaica**, a temporary employment programme was created for regular cleaning of public sector long-term care facilities, and spaces were set aside in those facilities for isolation of symptomatic residents. Also, a multisectoral exercise between multiple State and private sector agencies facilitated deep sanitization of public long-term care facilities (79).

In **Indonesia**, prevention measures in long-term care facilities include knowledge-sharing on hygiene principles with care workers and residents, regular disinfection and ventilation, and abstaining from sharing personal medical equipment. Residential long-term care facilities have put in place a registration system and do not allow visitors with symptoms of COVID-19 to enter the premises (95).

In one region of **China**, after the severe acute respiratory syndrome epidemic, the regional authorities published the first guidelines on prevention of communicable diseases in residential long-term care facilities for the elderly in 2004, and required all operators of long-term care facilities to designate an infection control officer to coordinate and implement infection control measures within the facility, according to the guidelines (65).

In **Germany**, the Robert Koch Institute recommends that domiciliary care workers wear face masks when providing care and that they regularly monitor their health. Additional equipment should be made available if the person they care for shows COVID-19-related symptoms (96).

In **the Netherlands**, some home care workers are organized into special “Corona teams”. These teams look after people with COVID-19, while other teams care for people without infection (80).

2.7 PRIORITIZE TESTING, CONTACT TRACING AND MONITORING OF THE SPREAD OF COVID-19 AMONG PEOPLE RECEIVING AND PROVIDING LONG-TERM CARE SERVICES

2.7.1 The challenge

Many countries have experienced shortages in testing capacity as hospital services were prioritized

In many countries there have been shortages of testing capacity as initially the available capacity was used mostly in hospitals, leaving providers of long-term residential and community services with difficulties in detecting people who had COVID-19. This approach is increasingly understood to have been a major problem, given the high rates of pre-symptomatic or asymptomatic people who have COVID-19 and could be spreading infection.

Effective contact tracing in long-term care settings requires coordination and collaboration between long-term care providers and the relevant health authorities

Effective testing, tracing and monitoring of COVID-19 in long-term care require coordination and collaboration between long-term care providers and the relevant health authorities. However, due to challenges in governance, such coordination has been difficult in the initial phases of the response. A growing number of countries are now including contact tracing in guidance for the long-term care sector and are developing apps and other systems to support contact tracing.

Lack of systematic monitoring of the health status of people receiving and providing care

Regular monitoring enables staff to detect changes in people's health status, including the development of atypical symptoms (13), and to respond faster if a person with care needs or staff develop symptoms of COVID-19.

IMPLICATIONS IN THE CONTEXT OF COVID-19

- ➔ Long-term care facilities have become a blind spot for priority testing, tracing and monitoring of COVID-19
- ➔ High rates of asymptomatic people who have COVID-19 have made early recognition and subsequent appropriate steps difficult

2.7.2 Key actions

Whole sector

- Ensure testing data are aggregated and shared with local and national public health agencies so that the pandemic is managed at both the population and individual levels.
- Ensure contact tracing and isolation based on national guidance, with reference to WHO guidance on contact tracing in the context of COVID-19 (36, 97).
- Trace any clusters of infections or deaths of people in long-term care facilities or amongst those receiving home care services.

- Do not rely on symptoms alone, particularly “typical” cough and fever symptoms, when screening for COVID-19, and ensure that staff are trained in identifying other atypical symptoms, especially in older persons (36).
- Ensure that the health of people receiving and providing long-term care is monitored so that the development of symptoms (including atypical symptoms) can be detected quickly.

Long-term care facilities

- In areas with ongoing or suspected community transmission, rigorous testing of both residents (including new admissions) and staff and tracing of close contacts are essential to develop isolation policies.

Community-based care

- Ensure that people providing and receiving care in the community as well as their household members have access to testing and contact tracing, and have support if they need to isolate (87–88).
 - Include household members of people with care needs in symptom monitoring.
-

Examples

In **Denmark**, both symptomatic and asymptomatic residents and staff in long-term care facilities can access testing at regional hospitals (since 12 May 2020). Even before that date, residents and staff were tested if there was an outbreak in a residential long-term care facility. If one resident shows symptoms, all residents and staff are tested within 24 hours and retested after seven days. If a staff member tests positive, all residents in the same area are also tested (98).

In **the Netherlands**, all family caregivers that experience symptoms of COVID-19 can get tested (since 18 May 2020). In addition, family carers have been able to access free PPE since 19 May 2020 if they support vulnerable people (aged 70 years and older, with chronic conditions) who experience symptoms of COVID-19 and where personal assistive care (with less than 1.5 metres distance) is required (80).

In **Malaysia**, all registered and unregistered long-term care facilities have undergone testing for COVID-19 (99).

In the **European Union**, the European Centre for Disease Prevention and Control guidance recommends testing strategies that distinguish between “affected local areas” (random testing of residents and staff) and “unaffected areas”. Affected areas are those with actual or presumed continuing community transmission (73).

2.8 PROVIDE SUPPORT FOR FAMILY AND VOLUNTARY CAREGIVERS

2.8.1 The challenge

Family caregivers provide an important share of care, but support such as respite care, training or care leave schemes remain limited and without compensation

An important share of long-term care across countries is provided by family caregivers who provide care directly, and also help coordinate and complement formal services. In countries without established formal long-term care services, family caregivers provide almost all long-term care. Caregivers usually do not have access to any training for their role.

Some countries recognize the impact of caregiving and offer support such as paid care leave, flexible work arrangements, respite care, training and psychological interventions, as well as cash benefits to mitigate negative impacts (29). However, access to these support structures remains limited in most countries and caregivers traditionally provide support without compensation, training or support (1). Even though caregivers' important contribution is increasingly recognized, available support structures and financial support were already limited before the COVID-19 pandemic (100).

The provision of intense levels of care has generally been associated with lower income and ultimately higher poverty rates, as well as poor mental health

The largest share of this care is provided by women (61%), though the share of male caregivers increases with age (74). There are also many young (including children) and older caregivers who support family members with long-term care needs. The provision of intense levels of care has generally been associated with reduced labour force attachment (for those of working age), lower income and ultimately higher poverty rates (101). In addition, reduced income and lack of pension contributions exacerbate the risk of vulnerability and poverty in old age. Caregivers also have a higher prevalence of mental health problems (101).

The COVID-19 pandemic has meant that some caregivers have had to adjust or give up their jobs to provide care or to avoid exposing the person they support to the risk of a COVID-19 infection. Caregivers working in the informal economy may also have experienced reduced working opportunities due to restrictions, posing a risk to their income. Caregivers also require support for the financial impact of the pandemic (102).

The discontinuation of residential care options has left many family caregivers with increased responsibilities and without their usual support structures

The COVID-19 pandemic has led to the closure of many day and respite care options, including community-based or short-term care, leaving many caregivers with additional responsibilities and without their established support structures. It is important to understand the issues caregivers face during this pandemic and how they can best be supported (102).

Caregivers need to be able to get to the person with care needs, have access to information, PPE and testing, and be supported in developing contingency plans

In many countries, government and NGOs have responded to this need by providing guidance and resource documents on hygiene measures to prevent infection and how to respond if the person with care needs or the caregivers themselves develop symptoms. Issues that have emerged during the pandemic include the need for caregivers to have permission to travel due to their care responsibility (78–79), supporting caregivers with access to testing and PPE (80), and developing contingency plans in case they can no longer continue to provide care (77).

Changes in care needs and violence or abuse towards the caregiver

Many caregivers are coping with changes in the needs of the person for whom they care (which may be due to infection or to the impact of the restrictive measures). Also, disruption to the normal routine may cause anxiety and stress in people with care needs, increasing pressure on caregivers (29). The COVID-19 pandemic has brought domestic violence and abuse to the surface (38). Family caregivers may also experience violence and abuse in their care relationship and require support (103).

IMPLICATIONS IN THE CONTEXT OF COVID-19

- ➔ Many caregivers have additional responsibilities without established support structures (such as day and respite care options)
- ➔ Social and physical distancing measures across countries are having negative health impacts on caregivers
- ➔ Even though caregivers' important contribution is increasingly recognized, available financial support remains limited
- ➔ Caregivers experience difficulties in getting the necessary supplies, as they cannot easily leave the person they support alone
- ➔ Access to PPE and testing has largely been absent for family and voluntary caregivers
- ➔ Prolonged isolation, care responsibility without breaks, concerns about the person with care needs, worries about contingency care in case the caregiver becomes incapacitated, as well as violence or abuse towards the caregiver, have implications for caregivers' mental health

2.8.2 Key actions

Whole sector

- Record the main caregiver in health and long-term care records so that they become recognized as an important source of information and support.

Long-term care facilities

- Enable family caregivers who provide psychological and practical support for people living in long-term care facilities to continue such roles through supportive measures that ensure the safety of the caregivers.

Caregivers

- Provide information, training, support and, if possible, respite care at national level to caregivers, particularly those caring for older people living with dementia, including information on how to manage increased caregiving responsibilities and stress. Consider establishing a telephone helpline or online portal to offer advice, information and support (104).
- Consider rolling out an assessment to monitor family caregiver needs.
- Develop clear guidance for family caregivers on when and how to self-isolate.
- Increase vigilance and monitoring of domestic violence and support for family caregivers.
- Ensure access to PPE (without family caregivers bearing the inflated cost) and to equipment and medications.
- Explore new ways of providing support services to caregivers through technology, and support caregivers in accessing relevant technologies.
- Introduce or expand financial and psychosocial support for family caregivers.
- Provide bereavement support and ensure careful communication on decision-making with family.

Country examples

In **Brazil**, NGOs (such as the Brazilian Society of Geriatrics and Gerontology and the Brazilian Alzheimer's Association) have published technical and educational caregiver guidance documents. A booklet has been prepared by FioCruz and other health-related organizations to educate caregivers of older people on preventive and protective measures for COVID-19. There is also a website by the Ministry of Women, Family and Human Rights dedicated to the provision of information for people with rare conditions and disabilities and their caregivers. A collaboration between the Ministry of Health and the Pan American Health Organization has developed a video campaign to support the mental health of people in Brazil who struggle with feelings of isolation, loneliness and distress. NGOs, such as the Alzheimer's Association, provide helplines and online forums. Other groups have organized psychosocial activities (105).

In **India**, guidelines issued by the Indian Ministry of Social Justice and Empowerment on 27 March 2020 recognized the importance of caregivers being able to get to the people they support. It was recommended that caregivers should be issued with passes that enable them to travel during the period of movement restrictions. Also, NGOs (such as the Alzheimer's and Related Disorders Society of India, Nightingales Medical Trust and Silver Innings) and specialist services (National Institute of Mental Health and Neuro-Sciences, Cognitive Disorders Clinic) offer information and resources for caregivers of people living with dementia. The Nightingales Medical Trust provides the DemKonnnect app, which offers expert advice to caregivers. The Ministry of Health and Family Welfare offers a psychosocial and behavioural helpline. In addition, it has provided videos (including on meditation and yoga) for stress management and mental health tips for different age groups on its website (78).

In **Ireland**, the Dementia Services Information and Development Centre has provided resources for caregivers, including suggested activities for people living with dementia to mitigate the impact of social isolation. The Alzheimer Society of Ireland also offers relevant resources for support and information. Caregivers in receipt of the means-tested carer's allowance continue to receive payments during the COVID-19 pandemic. In addition, working caregivers in receipt of the carer's allowance who have lost their jobs due to the pandemic can also access the new pandemic unemployment payment of 350 euros. Similarly, Family Carers Ireland has developed guidance for the development of an emergency plan for caregivers (77).

In **Germany**, the period for receiving long-term care allowance (Pflegeunterstützungsgeld) to respond to an emergency care situation in the family or to organize care arrangements has been doubled in response to the COVID-19 pandemic from 10 to 20 days (until 30 September 2020). The right to stay away from work to respond to an acute care situation has also been extended to 20 days. People who usually receive in-kind services that have become unavailable during the COVID-19 pandemic (such as day care) can be reimbursed to finance replacement care (96).

2.9 PRIORITIZE THE PSYCHOLOGICAL WELL-BEING OF PEOPLE RECEIVING AND PROVIDING LONG-TERM CARE SERVICES

2.9.1 The challenge

Many people with care needs experience a change to their routines and prolonged periods of isolation

Many people, particularly older adults, with long-term care needs have been isolated in homes or facilities for many weeks, leading to reduced social contact and disrupted and changed routines. Some people with long-term care needs, such as people living with dementia, experience changes in their physical and cognitive status. Rapid changes to their routine may also increase their vulnerability to pre-existing conditions (84, 104).

Specifically, in long-term care facilities, residents have struggled with not being able to socialize with fellow residents or to receive visits from their family and friends. Families are also extremely distressed that they are not able to visit and oversee the resident's care.

Long-term care facilities have recognized the importance of supporting residents with social contacts and have introduced innovative solutions, such as technical tools that enable virtual contact with their families and friends.

Sharp increase in the risk of violence against older people

Violence against older people, who are already bearing the brunt of this pandemic, has risen sharply since the beginning of the COVID-19 pandemic and imposition of restrictive stay-at-home measures. Violence is occurring in homes, in institutions such as long-term care facilities, and online, with a surge in scams directed at older people (106).

Long-term care workers experience substantial pressure on their mental health during the COVID-19 pandemic

Long-term care workers (compensated through pay) have experienced sustained pressure to provide care to vulnerable groups during the COVID-19 pandemic, and have worked hard to prevent the spread of COVID-19 to the people they assist. Many will have experienced traumatic situations and multiple bereavements. This leads to substantial pressure on their mental health. In the Netherlands, a survey by the Dutch Nurses' Association (V&VN) found that 69% of community carers have felt greater pressure on their mental health during the COVID-19 pandemic. Among the 3325 respondents, 28% reported that there was no mental health support provided by their employer (80). Specific interventions to support the well-being of care workers are largely lacking.

Some countries have recognized the mental health toll that the COVID-19 situation in long-term care facilities has taken on their staff and have put in place interventions to support the mental health of staff. In the United Kingdom, efforts have been made through support services to enhance the well-being of care workers.

Migrant carers, particularly those who were commuting to provide care in other countries, may have found themselves either unable to return home after their shifts or unable to go to work (and therefore be paid) as countries closed their borders, leading to considerable hardship (76, 107).

Family and voluntary caregivers experience great care responsibility and isolation, while their usual support services have largely been suspended

Many family caregivers have been isolating with the person they care for to protect them from a COVID-19 infection. This has left them feeling disconnected from their social networks. In addition, their usual support structures (such as day care, home care, other family caregivers and carer support groups) have been reduced in frequency or suspended, leaving family caregivers without important social contacts and sources of practical support.

In some countries, helplines, virtual counselling and carer support groups have been established to support caregivers' psychosocial well-being during the COVID-19 pandemic.

IMPLICATIONS IN THE CONTEXT OF COVID-19

- ➔ There has been a significant impact on the mental health of the staff of long-term care facilities, family and voluntary caregivers, and people with assistive care needs
- ➔ Many residents of long-term care facilities have struggled with not being able to socialize with fellow residents, to participate in regular social activities, or to receive visits from their family and friends
- ➔ Specific interventions to support the well-being of people providing and receiving care are largely lacking

2.9.2 Key actions

Whole sector

- Establish an intersectoral working group to monitor long-term care staff stress and burn-out, and assess and implement strategies to provide mental health and psychosocial support to staff delivering long-term care.
- Establish a dedicated helpline for mental health and psychological support for anyone who requests it.
- Consider providing guidance on training care staff and volunteers to improve communication skills on sensitive issues such as end-of-life decisions, death, dying and bereavement.
- Encourage long-term care providers on the use of screening tools, review staffing procedures (such as flexible schedules and work breaks) to better manage the burden of care, and seek to reduce the use of physical restraints.
- Ensure mental and emotional support is available from mental health professionals and family caregiver networks, using digital media when required to support recipients and providers of care.
- Support the monitoring of violence towards older people.

Long-term care facilities

- Establish clear visiting policies that provide balance between IPC measures and the need for people to maintain their psychological well-being (enable residents to have visitors while minimizing the risk of COVID-19 entering long-term care facilities).
- Facilitate residents' contact with family and friends by phone, the Internet or written messages if access is restricted.
- Increase recruitment of volunteers to help with providing social interaction for isolated residents.

Community-based care

- Ensure access to and scale-up of resources for migrant live-in care workers.
 - Encourage and enhance psychosocial support structures for family caregivers.
 - Consider introducing mental health first aid training for volunteers and community members.
-

Country examples

In **Chile**, the National Service for Older Persons and the Society of Geriatrics and Gerontology have issued videos and graphics to support older people and family caregivers to cope with the COVID-19 situation. This material includes information on the use of PPE, distancing and mental health recommendations (108). It also offers templates to support the organization of community support for people needing help with the basic activities of daily living (109).

In **Mexico**, the Ministry of Health implemented a mental health support campaign, which includes a rapid telephone assessment, to provide support strategies and to make referrals for specific support. Part of the strategy includes a campaign targeted at health care workers (110).

In **Kenya**, some NGOs have moved to virtual peer support. However, poor connectivity in some areas, the cost of purchasing Internet bundles, and online fatigue pose challenges to efforts to support family carers. The Ministry of Labour and Social Protection published guidance for long-term care facilities, which explicitly states that staff should ensure that residents can maintain regular communication (through mobile calls or online chats) with their families and social networks, and should promote the well-being of residents by establishing regular routines and reducing interruptions to those (111).

In **Malaysia**, staff of day care centres continue to look after the people they support through video calls, as well as sharing activities and exercise videos (99).

In the **United Kingdom**, the COVID Trauma Response Working Group has developed guidance for managers and service planners concerned with looking after staff of long-term care facilities who may have experienced trauma (112).

2.10 ENSURE A SMOOTH TRANSITION TO THE RECOVERY PHASE

2.10.1 The challenge

Loss in public confidence in long-term care facilities

The COVID-19 pandemic has disproportionately affected people who live in long-term care facilities, and the share of deaths in those facilities appears to increase with the number of people affected in the community. This suggests that as long as there is community transmission of COVID-19 locally, long-term care facilities are at high risk of infection and large numbers of deaths.

There are concerns in many countries about the loss in public confidence in long-term care facilities, and the possible negative impacts that might result if people who would benefit from living in a long-term care facility fail to do so because of fear. This may have negative consequences for these persons, for their families, and also for the financial viability of providers of long-term care facilities.

Movement restrictions and other shielding measures in long-term care facilities

One of the first measures adopted in almost all countries has been restricting visitors to long-term care facilities. While this measure is relatively easy to implement, it is increasingly recognized that it has an enormous impact on the well-being of both the residents of long-term care facilities and their families, and that, particularly where the resident has dementia, a lack of understanding of why the visits have stopped may generate additional distress. Concerns have also been expressed that many family members provide care in their regular (sometimes daily) visits, and that not allowing them to visit at a time when the staff of long-term care facilities may already be overburdened due to increased complexity of care and lower staffing ratios may compound staffing problems.

Difficulties in monitoring quality of services in long-term care facilities

Another concern is that family member visits have stopped at a time when many countries have suspended inspections. Families may be concerned about the quality of care the residents are receiving, and not being allowed to visit may exacerbate their fears. Ensuring safe visiting is increasingly recognized as a key step in rebuilding trust in long-term care facilities.

IMPLICATIONS IN THE CONTEXT OF COVID-19

- ➡ Lack of exit strategy on restrictive measures applied to long-term care facilities
- ➡ Lack of monitoring quality of care within long-term care facilities when movement restrictions are implemented for those facilities

2.10.2 Key actions

Long-term care facilities

- Make available surveillance mechanisms to monitor the quality of care within long-term care facilities during implementation of public health and social measures.
- Make available guidance on thresholds as to when and how to phase in or out isolation of residents and loosen restrictions on visitors.
- Establish clear criteria on when and how people living in long-term care facilities can move to and from hospitals to protect both staff and other residents.
- Ensure that the needs of long-term care residents are considered in providing acute, primary and community health services, and that pre-COVID-19 levels of support from primary care and community nursing are reinstated as early as possible.

Community-based care

- Ensure that protocols are being developed so that people receiving community care (for example, day care) can access these services again.

Country examples

In **Malta**, day care services started again on a rotational basis on 1 June 2020. People with care needs receiving no services were given priority. Strict hygiene procedures and distancing measures were put in place. For example, staff and people with care needs keep shoes at the day care facility and change when they leave. People with care needs have to wear masks and visors while attending the centre. Staff also wear visors throughout the working day. In addition, people receiving and providing care have their temperature monitored (58).

In **Denmark**, people could continue to visit residents receiving end-of-life care while adhering to hygiene protocols. Since 24 April 2020, residents in long-term care facilities can receive visitors in the outdoor areas (98).

In **Germany**, restrictions around visitors started to be relaxed again in May 2020. While specific rules on the number of people visiting and the frequency and lengths of their visits vary between federal states, all states require that long-term care facilities put clear infection prevention measures in place. Visitors also have to register so that they can be identified for contact tracing if this becomes necessary (96).

2.11 INITIATE STEPS FOR TRANSFORMATION OF HEALTH AND LONG-TERM CARE SYSTEMS TO APPROPRIATELY INTEGRATE AND ENSURE CONTINUOUS, EFFECTIVE GOVERNANCE OF LONG-TERM CARE SERVICES

The COVID-19 pandemic has highlighted fragmentation between long-term care services within health care systems. This fragmentation, along with inherent weaknesses in the current overarching governance structure for long-term care, has led to devastating consequences for long-term care facilities during the COVID-19 pandemic.

It is with urgency that we need to transform health and long-term care systems so that long-term care services are readily integrated and provided alongside the traditional continuum of care: promotion, prevention, treatment, rehabilitation and palliation.

It must be emphasized that assistive care, defined in this document as assistance provided to help a person perform a particular task to maintain functional ability and preserve independence, is considered an essential service that helps to promote ageing in place and ensure that a person can continue to do what they have reason to value even after significant declines in physical and mental capacity.

The WHO Global Strategy and Action Plan on Ageing and Health, adopted in 2016, states that “Every country should have a sustainable and equitable system of long-term care” (44). The Decade of Healthy Ageing (2020–2030) also emphasizes access to long-term care for older people who need it (113).

Although long-term care is not just for older people and includes a diverse range of users, the fundamentals are the same: providing services to those that are in need of long-term care in order to ensure a life consistent with their basic rights, fundamental freedoms and human dignity.

The following actions reflect the lessons we are learning from the COVID-19 pandemic to realize sustainable and equitable long-term care for all.

Key actions

- Ensure legislation and establish national strategy and frameworks on long-term care.
- Strengthen relationships between different levels of government involved in long-term care and health care and develop concrete vertical and intersectoral coordination mechanisms.
- Integrate regular national data collection of health and long-term care systems to enable systemwide evaluation and monitoring.
- Ensure sustainable and equitable financing mechanisms for long-term care that protect people from catastrophic costs of care.
- Ensure integrated person-centred care pathways spanning the health and long-term care continuum to enable people with long-term care needs to receive comprehensive care.
- Ensure continuous training and improved working conditions for the long-term care workforce.
- Introduce and expand financial and in-kind support for family and voluntary caregivers.
- Identify mechanisms to ensure quality services in the unregulated long-term care sector and strengthen accreditation.
- Ensure health sector oversight of long-term care facilities to prepare for future pandemics.
- Promote research building on lessons learned from the COVID-19 pandemic to address weaknesses in the health and long-term care system.



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Annex 1. Methods

Living systematic review

A living systematic review was undertaken, aiming to synthesize early international evidence on mortality rates and incidence of COVID-19 among people who use and provide long-term care. The review was registered with Prospero (CRD42020183557) and includes studies identified through database searches conducted on 15 May 2020 and updated up to 5 June 2020. The methods and findings have been published in full in medRxiv. Seven databases were searched (MEDLINE; Embase; CINAHL Plus; Web of Science; Global Health; WHO COVID-19 Research Database; medRxiv) to identify all studies reporting primary data on COVID-19-related mortality and incidence of disease among long-term care users and staff. In addition, evidence on country-level mortality rates was identified from LTCcovid.org, an international network of long-term care experts. Studies not focusing on long-term care were excluded. Included primary studies were critically appraised and results on number of deaths and COVID-19-related mortality rates, case fatality rates, and excess deaths (co-primary outcomes), as well as incidence of disease, hospitalizations, and intensive care unit admissions, were synthesized narratively.

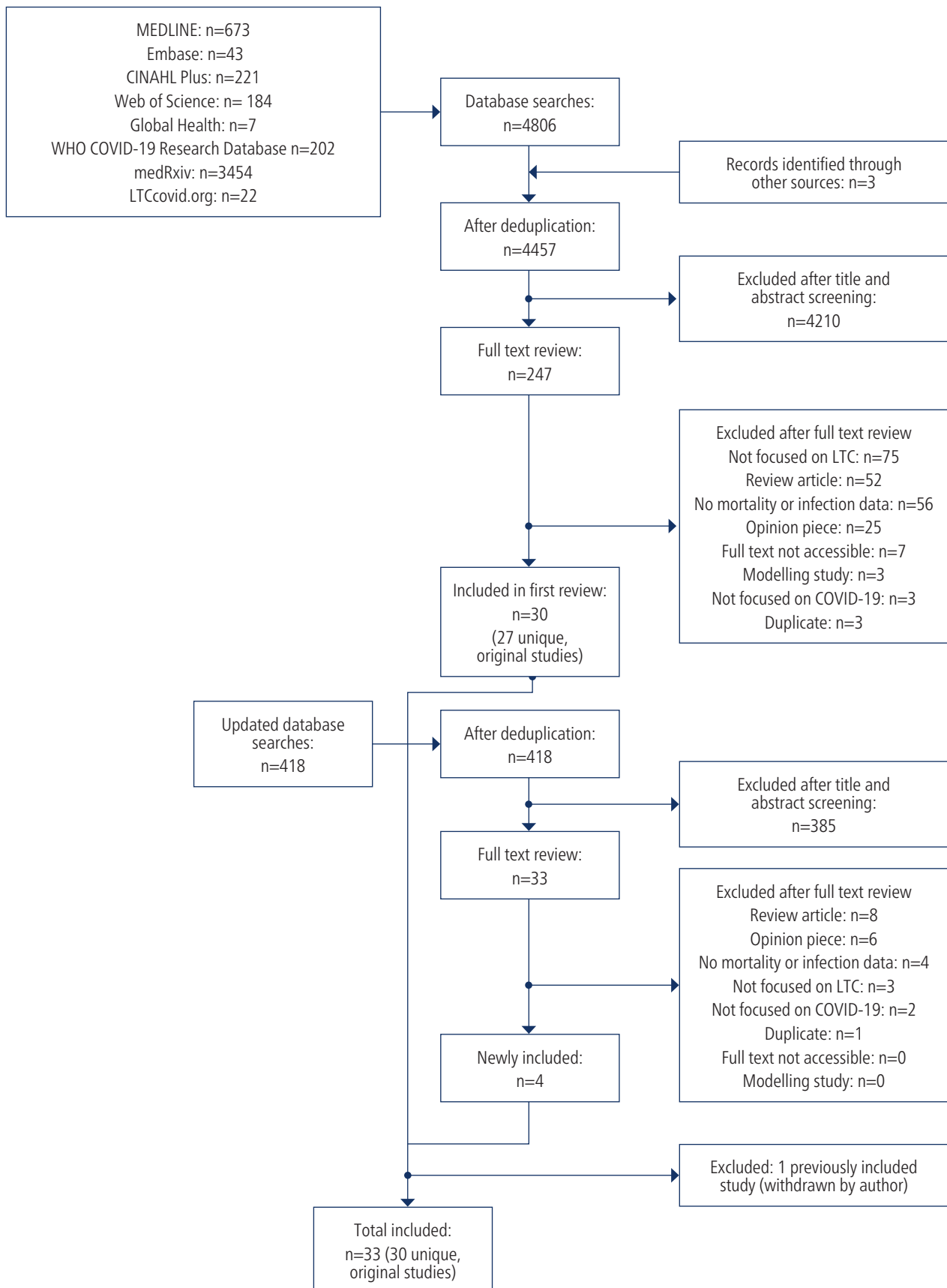
Title and abstract screening, and a full text review, were undertaken by three reviewers and records reporting on the same study or outbreak were combined. A standardized template was used to extract data at the study level, including information on study design; care setting (institutional versus community); how COVID-19 was diagnosed and confirmed; baseline characteristics of participants; absolute number of deaths and mortality rates from confirmed and suspected COVID-19 cases; case fatality rates; excess deaths; absolute numbers and rates of confirmed and suspected COVID-19; and rates of hospitalization and intensive care unit admissions among confirmed and suspected COVID-19 cases. All study participant characteristics and outcome data were extracted separately for long-term care users and staff. Information was also extracted on the proportion of asymptomatic cases at time of testing, and findings of studies comparing outcomes in long-term care users to others.

Due to heterogeneity in the definitions of numerators, denominators, and follow-up times across included studies, data were not pooled. Instead, results were summarized narratively and presented in tables, including information on sample characteristics, follow-up time, and case definitions, as appropriate. Where studies reported on overlapping populations, preference was given to those with larger sample sizes and longer follow-up times.

The quality of included primary studies reporting figures relating to mortality rates, case fatality rates, or disease incidence were assessed using the Joanna Briggs Institute critical appraisal tool for prevalence studies. Risk of bias across studies was not assessed.

A total of 33 study reports for 30 unique primary studies or outbreak reports were included (Figure A1.1).

Figure A1.1 Flow chart for selection of included primary studies



Pilot of a systematic review of effectiveness of interventions to mitigate the impact of COVID-19 on people who use and provide long-term care

A systematic review on the effectiveness of interventions to manage the impact of COVID-19 on people who use and provide long-term care is under development. While piloting the search strategy across seven databases (MEDLINE; Embase; CINAHL Plus; Web of Science; Global Health; WHO COVID-19 Research Database; medRxiv), 21 studies were identified that described responses to the COVID-19 pandemic and provided some sort of evaluation of effectiveness or aimed to assess characteristics of long-term care services associated with COVID-19 infection rates and associated mortality. There were five reports from the United States, three from Italy, two each from Canada, China, the Republic of Korea and Spain, and one report each from Belgium, France, Ireland, Singapore and the United Kingdom.

The interventions identified and target groups varied. Three of the studies related to pharmacological therapies in care homes (1–3), additional studies described the implementation of measures to prevent (China and Singapore) and contain (Canada, China, the Republic of Korea and the United States of America) outbreaks in care homes (1, 4–8), one study reported about prevention measures for community-based care in the United States (9), four reported on multifaceted organizational changes to deal with COVID-19 in long-term care settings, including multidisciplinary collaboration and coordination (6, 10–12), three were pilot studies for detecting COVID-19 through rapid point-of-care testing, pooled testing, and bedside chest ultrasonography (13–15), and one adapted an existing cognitive stimulation intervention for people with dementia to provide information and support in relation to COVID-19 (16).

These studies were mostly descriptive and, lacking a control group, were not designed to rigorously evaluate the effectiveness of implemented measures. Nevertheless, the prevention and outbreak management interventions described in the papers from China, the Republic of Korea and Singapore all reported successes in preventing or containing outbreaks.

Another three studies assessed the association between different characteristics of care homes and COVID-19 outbreaks and outcomes. Stall et al. found that for-profit status of nursing homes in Ontario, Canada, was associated with both the size of a nursing home outbreak and the number of resident deaths (17). However, for-profit status was not associated with a higher likelihood of an outbreak. Romero-Ortuño and Kennelly found moderate, statistically significant association between crude number of deaths and maximum occupancy in Irish care homes, but no statistically significant association was found for quality of care homes (18). Similarly, Abrams et al. did not find a statistically significant association between the reporting of at least one COVID-19 case in United States nursing homes and traditional quality criteria (19). However, a statistically significant association was found for larger facility size, urban location, percentage of African-American residents, non-chain status, and state.

Finally, two studies analysed the association between regional characteristics, including features of the long-term care system such as the proportion of private versus public long-term care beds and the availability of nursing home beds, and spread of COVID-19 in Italian regions (20–21).

Country reports on the COVID-19 long-term care situation

Country reports published on the LTCcovid website (an initiative of the International Long-Term Care Policy Network) were reviewed. The reports were produced by experts in long-term care, usually academics. The reports aimed to document the impact of COVID-19 on people who use and provide long-term care in each country, and the measures adopted to mitigate the impacts of the pandemic on this population. Information from these reports informed the examples of measures adopted by different countries.

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