

COVID-19 Nursing Homes Expert Panel

Consultation Survey

In line with the Terms of Reference for the establishment of the CoViD-19 Nursing Homes Expert Panel, the purpose of this group is to report to the Minister for Health in order to provide immediate real-time learnings and recommendations in light of the expected ongoing impact of COVID-19 with regard to Nursing Homes over the next 12-18 months.

As part of this process the Expert Panel is undertaking rapid consultative processes to engage with a range of key stakeholders through various means. There is a short timeframe for the completion of its considerations, including a broad range of actions required to meet its purpose, including data and evidence gathering and analysis, stakeholder feedback and relevant deliberations and the development of a report to the Minister. Therefore, the Panel is conscious of the need to progress its work in a timely manner.

With this in mind, you are invited to participate in a concise, focused engagement process by completing this survey. **Please abide to the 250 word limit per section.**

Instructions for use:

- The form may be typed or handwritten, bearing in mind recipients' ability to interpret the submission for processing and inclusion in consideration
- For tick boxes (b) – please select one only under each question
- For free-text boxes – please limit submissions to 250 words per question, and make use of bullet points and brevity to aid the impact of your submission

All submissions submitted for this purpose are subject to release under the Freedom of Information (FOI) Act 2014.

Personal, confidential or commercially sensitive information should not be included in your submission and it will be presumed that all information contained in your submission is releasable under the Freedom of Information Act 2014.

Your name (optional): Bernadette Rock

If on behalf of an organisation, Organisation Name (required):

The Alzheimer Society of Ireland

My situation is best described as (please tick one only):

Myself, as a:	
Resident / patient	
Family member	
Workers and staff Policy and Research Manager	
Other: _____	

My experience pertains to (please tick one only):

First-hand experience	
Witness	
Other: _____	

Section 1: Key Learnings and actions – COVID-19 and Nursing Homes

Based on your knowledge or experience, what are the **key lessons** for the immediate term arising from the experience of the COVID-19 pandemic to date?

Dementia is a complex neurological condition and public health guidelines are difficult for many people living with dementia to adhere to due to cognitive impairment. People with dementia should be given particular consideration in relation to public messaging around COVID-19.

Age is by far the strongest risk factor for dementia and for COVID-19, meaning that many people living with dementia are likely to contract and die from COVID-19. It is concerning that data has not captured the mortality rate of COVID-19 among people with dementia in both nursing homes and in the community, and this should be immediately addressed.

In Ireland, residential care settings have been adversely impacted by COVID-19, where up to 72% of residents are people living with dementia. Special safeguarding measures, both short and long-term, should be put in place immediately to safeguard this cohort.

Research carried out by The ASI shows that cocooning for people living with dementia is particularly difficult and family carers are at significant risk of social isolation, increased anxiety, stress and loneliness. Additional supports are urgently required to address these challenges.

The temporary cessation of dementia services such as day care, Alzheimer cafés and support groups has adversely impacted people with dementia. Investment in supports and services is urgently needed to support this cohort.

Public policy has not focused on supporting people living with dementia and family carers who may be under increased pressure due to the cessation of services and supports in addition to the anxiety and stress of living through a global pandemic.

Based on your knowledge or experience or key learning, what **key actions** or measures do you think are required for the **short, medium and long term to safeguard residents** in nursing homes, against the impact of COVID-19?

Addressing need: Among people with dementia social contact, attachment, pleasurable activities, choice, control, and connectivity are all very important. Yet, given the Irish government's cocooning guidelines for those over 70, the latter will have a profound impact on quality of life. This coupled with the cessation of group recreational activities in nursing homes, and the absence of regular visits from family members and exposure to familiar faces of close relatives will all adversely affect well-being. In the short to medium term, the immediate needs of people with dementia, arising from recent restrictions in nursing homes needs to be understood and addressed.

Staff training: In Irish residential care settings significant staff shortages have occurred. Fostering a sense of belonging and familiarity with newly appointed staff recruited at short notice to back-fill front line positions is not easy for people with dementia. Some of these staff may have had little or no training in dementia and may be unfamiliar with residents' life stories. There is an immediate need to provide dementia specific training to staff and to ensure nursing homes have sufficient staffing ratios and that the well-being of staff is adequately upheld.

Integrated care: In the long term nursing home care should be viewed broadly in terms of the wider spectrum of all available services and supports operating in an integrated way, and should also include the role of family members, many of whom provide care to their loved ones in nursing homes. Nursing homes, including private facilities, should be integrated into the wider framework of health and social care and considered part of integrated care pathways to include nursing homes visits. Allied health care professional should also be involved in older people's care in nursing homes, as they are in communities. There should be clear responsibility and oversight for all care facilities for older people at both regional and national level.

Section 2: Public Health Measures Priorities

Describe what you think are the existing **and** additional **priority national protective public health measures** for nursing homes in the context of COVID-19

Complexity of dementia: Many of the restrictions introduced to nursing homes to cope with COVID-19 are having detrimental emotional and psychological effects on people with dementia in terms of social isolation and loneliness, according to ongoing ASI research. Many people with dementia do not understand COVID-19 advice relating to social distancing and visiting restrictions and do not understand why family members stopped or limited visiting. While some visiting restrictions have been lifted, the existing restriction needs to be considered from the perspective and complex needs of people with dementia.

Person-centredness: Every effort should be made to preserve the choice, autonomy and needs of people with dementia during a pandemic, and public health measures should reflect these principles. People with dementia are a vulnerable cohort and restrictions that are implemented need to be aligned with a person-centred approach. Public health measures for nursing homes should give more significant consideration to the role of families, and the voice of people with dementia and family carers should be included in developing public health measures for nursing homes.

Responsibility: The role of the COVID-19 Lead in nursing homes should be continued, and this role should include dementia training and awareness of the complexity of dementia. While HIQA currently address and approach nursing homes in a generic way, dementia should be taken into account as a disease area in itself that requires a particular response due to the complex nature of the disease and its challenges. Increasing the frequency of thematic inspections and a focus on dementia care in standard inspections should also be considered in order to support the needs of this vulnerable cohort.

Other relevant matters you wish to bring to the attention of the panel.

Dementia can be an extremely frightening condition for the individual, and familiarity, a sense of belonging, routine and consistency are crucial for good quality dementia care and for the preservation of personhood. Antipsychotic medication should be the last resort in responding to these behaviours as the use of such drugs can have very deleterious consequences. We do not know if this type of medication may be in more frequent use during pandemic periods in residential care settings, an issue that should be investigated.

The immediate need of people with dementia that are presenting now, arising from recent restrictions in nursing homes needs to be understood and addressed. This includes investigating the impact of restrictions for people with dementia, identifying strategies to support engaging remotely in care, and ensuring adequate PPE and oxygen supplies to cope future outbreaks of COVID-19.

Nursing homes should be part of a continuum of care that includes Intensive Home Care Packages, which have been shown to offer significant benefits to people with dementia.

Throughout this pandemic, people with dementia have been rendered invisible. Data on COVID-19 mortality in nursing homes and communities among people with dementia has not been collected, and the experience of this cohort has been largely overlooked. The absence of a dementia expert on this Nursing Home Expert Panel reflects the invisibility of dementia generally in Irish society and the lack of priority given to people living with the disease in nursing homes.