



Continuity of care for non-COVID patients Consultative Forum with Patient Advocacy Groups

Please complete this questionnaire and return to survey@mcirl.ie by Friday 12th June. The feedback provided will be collated with other submissions to form a discussion document for a Consultative forum. The output of this forum will be submitted to the Department of Health for their information and to inform their work programme. All information given in this consultation will only be used for the purpose to which you agreed to it being collected.

While the data may be identifiable, you have several rights under data protection legislation, including the right to access the data you have provided; the right to rectification the data you provide; the right to be erased from the dataset; the right to restrict or object to the processing of the data you have provided and to obtain and reuse your personal data (data portability). If you would like further information on your rights as a data subject, please contact our Data Protection Officer at dp@mcirl.ie. You also have the right to object to the processing of your personal data. You can contact the research team at survey@mcirl.ie if you wish to exercise any of your rights as listed above do any of the above and we would be happy to assist you. All analysis of the dataset is conducted in-house.

Participation in this consultation is entirely voluntary. Furthermore, if you do agree to complete the questionnaire now but change your mind after submitting your thoughts, you can contact the Medical Council (survey@mcirl.ie) and have your responses deleted from the dataset. If you have any further questions regarding this or other data held by the Medical Council, please contact dp@mcirl.ie.

Please note that all submissions may be subject to Freedom of Information requests.

Please keep submissions to two pages.

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What are the biggest concerns facing patients at present in respect of non-COVID 19 treatments and continuity of care?

Dementia is a complex neurological condition and COVID-19 guidelines are difficult for many people living with dementia to adhere to and follow due to cognitive impairment. Research carried out by the Alzheimer Society of Ireland (ASI) indicates that COVID-19 and restrictions associated with it are having a detrimental impact on people living with dementia and carers.

ASI research indicates that many people with dementia have had medical appointments cancelled due to COVID-19 and this is a cause of immense concern and frustration. Our research findings also indicate that many family carers are deeply concerned that their loved ones who have been recently diagnosed with dementia are unable to access important services such as speech therapy and cognitive stimulation therapy. Many are experiencing a notable deterioration in dementia symptoms, due to the temporary close of dementia services, such as day care, support group and home care, along with an increase in levels of anxiety and behavioural responses such as agitation and wandering. Many family carers are concerned that services may not re-open for some time and are experiencing immense stress and anxiety associated with increased workload.

When examining possible solutions to ensure adequate continuity of non-COVID 19 patient care in the current climate, what do you see as the key steps to be implemented?

The complex and particular needs of people with dementia need to be considered. People living with dementia, whether in respect of their dementia or other medical condition, will generally fare better in familiar surroundings. Conditions that may lead to confusion and distress will make their journey less successful. Therefore, prompt service, clear signposting, appropriate PPE that does not interfere with communication, encouraging carer assistance and familiar surroundings will all contribute to a more positive engagement and better outcomes.

It will be essential to provide an easily understandable care pathway for people with dementia to continue with their service and/or treatment and one that family carers will be able to understand and navigate.



What services do you see as a priority for restoration, as the immediate pressures on the health service due to COVID-19 begin to ease?

Research indicates that attachment, pleasurable activities, choice, control, and connectivity are important to people who have dementia. Yet, given the Irish government's cocooning guidelines for those over 70, (who constitute a sizeable proportion of those with dementia), it can only be speculated that the latter will have a profound impact on quality of life for people with dementia. Recent ASI research shows that the cessation of dementia services has negatively impacted people with dementia, leading to loss of routine, anxiety, frustration, loneliness, isolation and boredom.

ASI is of the view that dementia specific services which offer social inclusion and expression should be restored. This especially includes- day care, home care, and further services such as support groups, Alzheimer cafes and social clubs. People with dementia should be offered choice in relation services that are restored and these services should be person-centred and delivered by staff with sufficient dementia training.

What are the greatest challenges facing the continuity of patient care as the immediate threat of a COVID-19 surge passes?

One of the greatest challenges in relation to patient care and services is successfully re-engaging with service users and their carers, and doing so in a way that reassures them that it is safe to return to services akin to a pre COVID-19 routine.

The nature of dementia means that in many cases service users presentation and symptoms will have deteriorated as a result of their experience to COVID-19 and people with dementia may find reintegrating into previous services difficult.

There is a very real challenge for service providers to develop systems that will be both safe for and appealing to the service user. This needs to be achieved in a timely fashion.

There is a potential contradiction between, encouraging social interaction while still practising social distancing and use of PPE.



Other comments or feedback

There is a clear need to re-introduce people living with dementia into a more social and stimulating environment. Cocooning has led to serious challenges to persons with dementia and their family carers, who are at significant risk of social isolation, increased anxiety, stress and loneliness. 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 restrictions need to be considered from the perspective and complex needs of people with dementia. Helping people with dementia to re-integrate into services while ensuring their safety will be key.

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 both in nursing homes and in communities. In resuming services and care pathways, the complex needs of this cohort should be carefully considered. 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.