



OPEN LETTER

REVISED

Remembering people with dementia during the COVID-19 crisis [version 2; peer review: 4 approved]

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Abstract

This letter argues that we need to pay particular attention to people with dementia during this difficult time of the COVID-19 pandemic. Social distancing rules and cocooning for people aged 70 years and over are now in place in Ireland to slow down the rate of infection and protect vulnerable older people. This letter argues that we need, more than ever, to assert the personhood of people with dementia at this difficult time. That means more person-centred care and practical support structures for family carers to allow them to continue to care at home in a safe and life-enhancing way. New public broadcasting initiatives could create information and communication channels for people with dementia and their carers, as well as demonstrating empathy and solidarity with their predicament. Government, the Department of Health, the HSE and the voluntary sector have risen to the challenge of COVID-19 in all sectors of society. So too have ordinary citizens. Now we need to unite even more to create an unyielding commitment and adherence to the principles of decency, justice and equity in the allocation of scarce health and social care resources. By doing this, we will demonstrate our caring potential and capacity in a way that reflects our shared humanity, not only in the current crisis, but into the future.

Keywords

Dementia, COVID-19, crisis, response



This article is included in the [Coronavirus \(COVID-19\)](#) collection.

Open Peer Review

Reviewer Status

	Invited Reviewers			
	1	2	3	4
version 2 (revision) 28 May 2020				 report
version 1 16 Apr 2020	 report	 report	 report	 report

- Brendan Walsh**, Economic and Social Research Institute (ESRI), Dublin, Ireland
- Manuel Ruiz Adame Reina** , University of Granada, Melilla, Spain
- Brenda Gannon**, University Of Queensland, Brisbane, Australia
- Esme Moniz-Cook**, University of Hull, Hull, UK
INTERDEM, Hull, UK

Any reports and responses or comments on the article can be found at the end of the article.

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Author roles: O'Shea E: Conceptualization

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REVISED Amendments from Version 1

This new version contains suggestions made by the reviewers. The text includes the most recent number of COVID-19 cases and deaths in Ireland. It also includes extended narrative and appropriate references in respect of: nursing homes; carers; technology; and rights.

Any further responses from the reviewers can be found at the end of the article

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Things have changed and likely changed forever. We are in the throes of the biggest international crisis since the Second World War. Domestically, our lives have been turned upside down in the space of a few short weeks. At the time of initial submission of this letter (6th April, 2020), there were 5,364 cases of COVID-19 in Ireland and 174 people had died since the initial outbreak of the disease in the country ([Irish Government News Service, 2020](#)). By final refereed submission (15th May, 2020), these numbers had increased to 23,827 cases and 1,506 deaths respectively. An unprecedented lockdown is in place in the country, with citizens being confined to their homes in an effort to slow down the rate of infection. People aged 70 years and over are seen as particularly vulnerable to COVID-19 and therefore are the subject of specific national ‘cocooning’ measures designed to keep them safe but apart from their families and from the rest of the community. These measures are hard for all citizens and for older people in particular, but they are especially difficult for people with dementia, the majority of whom are likely to be 70 years and over. Dementia is a progressive and debilitating neurodegenerative condition which significantly impacts on memory, understanding and quality of life, as well as an individual’s ability to continue living independently.

There are currently an estimated 55,266 people with dementia in Ireland; 34,818 of whom are estimated to be living at home in the community ([O’Shea et al., 2017](#)). Many of these people may not even be aware that they have dementia and some of them will not be in regular contact with the health and social care system. Therefore, some people with dementia may be particularly vulnerable to COVID-19 infection, particularly if they have not heard about the disease, have heard but have forgotten, or have not understood the messages of cocooning and self-isolation coming from the government and the Health Service Executive (HSE). Therefore, we need to continuously reinforce the basic health messages of hand-washing, hygiene and social distancing for people with dementia and support them with these activities. That is the responsibility of everyone of us, not just family carers, the government and the HSE.

Just over 20,000 people with dementia live in residential accommodation, the vast majority of whom live in long-stay facilities, mainly in nursing homes ([O’Shea et al., 2017](#)).

From the outset, these people faced a worrying and uncertain future, as evident by the significant number of clusters of the virus in care home settings. The initial focus of emergency planning on the acute care sector resulted in a belated prioritisation of residential care settings, which has been addressed over time. But there has been significant mortality in the residential care sector since this letter was first submitted, not only in Ireland but internationally ([Pierce et al., 2020](#)). This has focused renewed attention on optimal care settings for dependent older people, including the role, potential, funding and integration of the residential care sector in overall social care, something that needs to be addressed when the current crisis abates ([O’Shea et al., 2019](#)). In the meantime, person-centred care, based on the tenets of a personhood philosophy ([Kitwood & Bredin, 1992](#); [Kitwood, 1997](#)), remains the best approach to providing meaningful support for people with dementia in residential care facilities. Protecting and respecting people with dementia, knowing their likes and dislikes, offering sensory stimulation, providing meaningful psychosocial activities and keeping people connected (however virtual) is more important than ever ([Kane, 2001](#); [Lawrence et al., 2012](#)).

There are an estimated 60,000 family carers in the community looking after someone with dementia in Ireland ([O’Shea et al., 2017](#)). Caring for a person with dementia compared with other caring roles places greater demands and strain on family members, at the best of times ([O’Shea, 2003](#)). The family caregiver of a person with moderate to severe dementia in Ireland is likely to be providing round-the-clock care, sometimes struggling to cope with distressing challenging behaviours, leading to emotional and psychological strain even in loving relationships ([Livingston et al., 2017](#)). Carers are facing additional difficulties now, given the new rules on social distancing and cocooning. It is very difficult to provide care at a distance, especially for a person with dementia who may not fully, or consistently, understand the reason for that distancing. We all can support carers by staying in touch through our own networks and offering emotional sustenance, sometimes listening is enough, and by providing more practical support with shopping and medicine supplies. Empathy is an under-rated virtue in difficult times and can be easily displayed through a phone call or social media communication.

What type of things matter at this time for people with dementia? People with dementia and their carers, like all of us, have physical needs so exercise is important, both for people living at home and in residential care facilities ([World Health Organisation, 2020](#)). People’s need for on-going emotional and psychological support should also not be under-estimated. We need to let people with dementia and family carers know how they can support and sustain themselves and that we are with them during the crisis. If we can have innovative new programmes for school-going children on national television, as is currently the case in Ireland (<https://www.rte.ie/learn/>), why not provide similar weekly educational programmes for dependent older people and their family carers now living in the same social circumstances. It would be wonderful to see public broadcasting initiatives providing information and advice on physical exercise in the home, sensory stimulation activities,

reminiscence-based ideas, brain health challenges, music therapies and creative opportunities for people with dementia (Moniz-Cook & Manthorpe, 2009). Local radio could offer similar programmes, drawing on the expertise of HSE staff and the Alzheimer Society of Ireland (ASI). We need to be creative in the way we communicate with the dementia community and provide practical information and support to address physical and emotional needs.

There is a strong and vibrant voluntary and community ethos in Ireland. This can be very beneficial during the current difficulties, but it needs to be harnessed and co-ordinated, something that the government is now doing (Irish Government News Service, 2020a). The ASI is doing powerful work in supporting people with dementia and their carers at this time and can be contacted at www.alzheimer.ie. They have a number of resources available to support people with dementia and family carers, particularly in relation to information, advice and helpful tips on how to deal with the COVID-19 crisis. Seniorline, ALONE and Age Action are other organisations that provide practical listening and support services for all older people that are invaluable at this time. In general, we need to make maximum use of both old and new technologies to connect with people with dementia and their carers and hopefully this current period will stimulate further innovation in regard to the use of technology (Manthorpe & Moniz-Cook, 2020). Assistive devices can be used to maintain people's independence and reduce worry for families, while digital reminiscence may be a means of promoting enjoyable activity in care settings (Subramaniam & Woods, 2016; Moon & Park, 2020).

The government, HSE staff, private providers, nursing homes, voluntary organisations and families have been doing their very best in trying circumstances to look after people with dementia. What's needed is for all of us to fully recognise the inherent personhood in people with dementia, especially their need for additional support, connectivity and communication during the crisis. This is the time when we must double up on our commitment to people with the disease, when we reassure them *that they will not be left behind*, to re-echo the words of our Minister for Health (Department of Health, 2020).

The message to citizens should be simple and straight-forward – social distancing and cocooning does not mean social isolation and the loss of citizenship for people with dementia. Human rights have never been more important, particularly the right to life, in all its forms, within the dementia population (Cahill, 2019). Alzheimer Europe's position paper on the allocation of scarce medical resources for intensive care services during the COVID-19 pandemic is, for example, firmly rooted in a rights-based approach (Alzheimer Europe (3rd April 2020)). Similarly, their recommendations on promoting the well-being of people with dementia and carers during the pandemic reflects a holistic, person-centred approach to the provision of services and supports (Alzheimer Europe (14th April 2020)). This is the blueprint for a virtuous approach to addressing the needs of people with dementia and carers during, and after, the crisis.

In Ireland, we need a strong and unbreakable social bond that we will not ration available resources by age, condition or income, but will continue to act on the basis of carefully assessed individual need and circumstances. Inter-generational solidarity is the corner-stone of Irish social policy. It must be especially nourished and protected at this time of extreme crisis. Our collective voice now can be the voice of the person with dementia, an echo chamber for the voice of our parents and grand-parents, a promise to our future selves, one that is strong in terms of an adherence to the principles of decency, justice and equity. By doing this, we will be able to allocate resources and our caring potential in a way that reflects our shared humanity. There will be time enough in the future to learn the lessons of COVID-19 in relation to the delivery, organisation and financing of health and social care in the country. Now is not that time, as we must support our government and front-line staff in dealing with the crisis. In doing so, we must especially protect those who can no longer remember, otherwise we, ourselves, will never be forgotten or forgiven.

Data availability

Underlying data

No data are associated with this article.

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[Reference Source](#)

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[Reference Source](#)

Open Peer Review

Current Peer Review Status:    

Version 2

Reviewer Report 02 June 2020

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Brendan Walsh

Economic and Social Research Institute (ESRI), Dublin, Ireland

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Health Economics. Inequalities. Health System Analysis. Cancer.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 29 May 2020

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Esme Moniz-Cook

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² INTERDEM, Hull, UK

The author has done an excellent revision to include important perspectives relating to the human rights and technology in his revision as well as updating the paper to the present date. I can definitely approve this revised paper.

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Version 1

Reviewer Report 11 May 2020

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**Esme Moniz-Cook**

¹ Psychology Ageing and Dementia Care Research, Faculty of Health Sciences, Department of Psychological Health, Wellbeing and Social Work, University of Hull, Hull, UK

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As cautious nuanced responses to emerging from the COVID-19 'lockdown' begin, older people with dementia living in care homes may 'have been left behind' in some countries. Additionally, worldwide campaigns to raise dementia awareness (The Lancet, 2017¹), has not overcome the pervasive influence of fear and nihilistic attitudes about dementia (Alzheimer's disease International 2019²). This thoughtful letter, therefore, remains timely, beyond its published date of a month ago. It highlights how this pandemic could have an important role in stimulating societies to take practical steps to counteract the double stigma of age and dementia (¹Moniz-Cook and Manthorpe 2009 p.16³) that continues to undermine person-centered care. To achieve this the author draws on the many creative evidence-based opportunities across Europe (¹Moniz-Cook & Manthorpe 2009) to assist families to live as well as they can despite the disabilities of age and dementia. These have broadened in scope over the past decade, with flourishing technological approaches to dementia care (Manthorpe & Moniz-Cook 2020; Ch. 9⁴). As strategies to maintain physical distancing have become the first-line action in the battle against COVID-19, online, digital, and other forms of assistive technology the author could pay particular attention to these growing innovations. The ENABLE project in Ireland (¹Moniz-Cook & Manthorpe 2009; Ch. 8) describes how assistive devices were used to maintain people's independence and reduce worry for families and digital reminiscence is a means of promoting enjoyable activity in care settings (Subramaniam and Woods 2016⁵; Moon & Park 2020⁶). Today people with dementia living at home counteract the effect of physical distancing, with online social interaction (<http://www.innovationsindementia.org.uk/the-coronavirus-situation/>).

An important point about the role of the media (p3 para.5) and volunteers (p.3 para4.) is made. *The toddlers who took on dementia* (<https://www.bbc.co.uk/programmes/b0b3kk1h>) demonstrates that the media can help to alter nihilistic public perception about psychosocial experiences of people with dementia. The call for harnessing co-ordination could, therefore, go further to counteract the pervasive stigma attached to dementia. For example, coordination of volunteer-led singing initiatives (<https://www.singireland.ie/news/sing-ireland-covid-19-update>) through television and other media; or clips of people enjoying outside 'walking' space with volunteers are emphases for recommendations

made by this letter.

Citizens living with dementia have learned much through their ongoing fight against the fear and uncertainty that travels with a dementia-diagnosis. Coordinated initiatives between volunteers and broadcasters could now offer them the opportunity to reciprocate, for example with visual media-led of how 'moments' (MacPherson *et al.* 2009⁷) of pleasure can encompass how people with dementia wish to live well (Øksnebjerg *et al.* 2018⁸) and contribute to their communities. The differing views about resources are missing. Perhaps the rights of people with dementia can be linked to Alzheimer Europe's position statement to scarce medical care (3rd April 2020)

<https://www.alzheimer-europe.org/Policy/Our-opinion-on/Triage-decisions-during-COVID-19-pandemic;/recommendations-for-other-care> (14 April 2020)

<https://www.alzheimer-europe.org/Policy/Our-opinion-on/Wellbeing-of-people-with-dementia-during-COVI>

¹First author name quoted by the author of this letter (pg 3 para 5) is incorrect: it should read Moniz-Cook & Manthorpe in text/reference list: Moniz-Cook E.D & Manthorpe, J. Eds.

Points to be addressed:

1. Author name (p.3 para. 5) /reference list revision: Moniz-Cook
2. Emphasis: Technology for social interaction, perhaps connecting volunteering and media activity.
3. Rights of people with dementia reflecting recommendations for better care; consider Alzheimer Europe's statement on scarce medical care (3rd April 2020)
<https://www.alzheimer-europe.org/Policy/Our-opinion-on/Triage-decisions-during-COVID-19-pandemic;/other-care> (14 April 2020)
<https://www.alzheimer-europe.org/Policy/Our-opinion-on/Wellbeing-of-people-with-dementia-during>

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Is the rationale for the Open Letter provided in sufficient detail?

Yes

Does the article adequately reference differing views and opinions?

Partly

Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Partly

Is the Open Letter written in accessible language?

Yes

Where applicable, are recommendations and next steps explained clearly for others to follow?

Yes

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 18 May 2020

Eamon O'Shea, National University of Ireland Galway, Galway, Ireland

Thank you for this review. I have briefly addressed the issues you raised in relation to references, rights and technology. Thank you also for the additional references.

Competing Interests: None

Reviewer Report 28 April 2020

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Brenda Gannon

Centre for the Business and Economics of Health, University Of Queensland, Brisbane, Australia

This letter is timely and well warranted, given the escalation of the COVID-19 escalating. 'No-one will be left behind' must not be just a statement, but must be followed up with meaning. This is particularly important for more vulnerable people in society, such as those with dementia. The basic teaching of health economics, is to fairly distribute scarce resources, ensuring efficiency, equity and social justice are adhered to in decision making. This letter precisely makes this argument. In the case of people with dementia, if they don't have their own voice, then their carers and society need to act, to ensure they are

not left behind.

The letter is written with sound theoretical foundations, ensuring the person is at the centre of care provided. The arguments are well set out and include appropriate references.

The language is appropriate, considerate and respectful. People with dementia are people, not patients, not old people, not aged and so on. This is a very nice aspect of this letter, making it a pleasure to read.

The practical proposals for broadcasting are great. The implementation of such would need further work and assurance that any intergenerational viewing would not be derogatory or make a person feel less a person, and more so a statistic. This comment arises from coverage I have seen in Australia, of a new program on TV that shows older people and children undertaking basic exercises - encouraging people at home to follow these, so all age groups (but especially young children and older people) can connect and then exercise together virtually.

While the idea is meant in good faith, the implementation requires way more thought on the theory behind it and how to demonstrate inclusivity, ability and not just categorise those aged 70 and over into one group, depicted as those who may be less mobile and frail. Many people aged 70 and over, and even 80 and over, are more agile than depicted in that programme. I hope RTE will bear this in mind and consult with relevant academics on implementing a fair and respectful broadcast.

Of course since this letter was written, there has been a rapidly evolving situation and unfortunately the mortality has increased significantly with 55% being those in nursing homes. It would be great to see a continuation of this letter, and update, to show how many of those had dementia and how many were either in the community or the nursing homes.

Lastly, social distancing is more vital than ever, but this can be done in a humane way, including people with dementia and also any other older people. If an older person is capable of going for a walk or their normal physical activity, then they should be allowed do so, as long as they respect the physical distance rules that apply to everyone, and ensure if they have any underlying condition that puts them at increased risk, then they should take that risk into consideration when planning their exercise. Overall, exercise and vitamin D are vital to good health and cocooning everyone, regardless of their level of frailty may therefore need to re-considered and the restriction loosened so that people can redeem their dignity and inclusion into society.

Is the rationale for the Open Letter provided in sufficient detail?

Yes

Does the article adequately reference differing views and opinions?

Yes

Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Yes

Is the Open Letter written in accessible language?

Yes

Where applicable, are recommendations and next steps explained clearly for others to follow?

Yes

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 18 May 2020

Eamon O'Shea, National University of Ireland Galway, Galway, Ireland

Thank you for this review. You have raised many important points. I have attempted to incorporate many of them in the final version, especially in regard to nursing homes.

Competing Interests: None

Reviewer Report 27 April 2020

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Manuel Ruiz Adame Reina 

Department of Applied Economics, School of Social Sciences and Law, University of Granada, Melilla, Spain

This paper underlines a relevant issue in this moment. The need of a personhood approach in the case of people with dementia when protective measures are taken such as the isolation to fight against Covid-19. From this initial issue other important questions arise, the role of the different social stakeholders to provide support to the people with dementia and their caregiver and how to assure that this support could be maintained in the future, not only in the current crisis.

This situation is completely new for everybody all over the world. Things have changed in a very short period of time and no health neither social system was ready to assume the stress test that a pandemic like this was going to be. In some countries such as Italy or Spain, for their demographic characteristics and for certain unsuccessful epidemiological measures, the number of people affected are proportionally greater than in Ireland, but in general, the Covid-19 has attacked with more aggressiveness to the older people, and mainly to people who live in nursing homes.

Isolation seems to be the most effective measure, but with people with dementia, as the author states, we must bear in mind the cases in which caregivers have to cope with behavioural disturbances, very common among fronto-temporal dementias and dementias with Lewy bodies. In those cases, the lockdown can be a very stressful situation for the people with dementia and for their caregivers.

The author also states the case of people in very mild stages of the syndrome in which people still have a certain level of autonomy and can live on their own. These people are a special group in a moment in

which the authorities command social distant measures that maybe they do not understand.

On the other hand, the author points out the role of the caregivers. They have to adapt to new circumstances, and maybe they do not have enough information about how to do it. The local authorities and the media can be a great support for them. Educational programs such as those proposed by the author could be very helpful.

From my point of view, this paper is a very interesting work that resumes some of the most relevant worries among caregivers, health and social stakeholders. It could very useful for policy makers. It merits to be indexed.

Points to be addressed:

The number of cases could be actualised in the final version at the time of publication.

Even though it is very widely used the term “social distancing”, in my opinion is more accurate to use “physical distancing”. The first one leads to thinking in emotional distancing, or even in a reduction of empathy with people with dementia and their caregivers.

It also could be interested to include (if possible) questions such as :

- How this situation affects to the caregivers in their working situation?
- How other family members change their attitude to give support to the main caregiver under these circumstances?
- How different clinical profiles (E.g. behavioural problems) can modify the need of support?
- Did the caregivers have enough access to protection equipment (E.g. gloves, masks...)?

Is the rationale for the Open Letter provided in sufficient detail?

Yes

Does the article adequately reference differing views and opinions?

Yes

Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Yes

Is the Open Letter written in accessible language?

Yes

Where applicable, are recommendations and next steps explained clearly for others to follow?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Health Economics. Dementias. Long Term Care. Social costs.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 18 May 2020

Eamon O'Shea, National University of Ireland Galway, Galway, Ireland

Thank you for your comments. I have briefly highlighted some of the carer issues highlighted by you in your review. They are all important questions that deserve a paper of their own - see paper by Phillips et al in HRB Open.

Competing Interests: none

Reviewer Report 20 April 2020

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Covid-19 affects the older and more vulnerable populations the most. This letter focuses on people living with dementia. This is a group with a higher susceptibility to the illness itself. This group has also seen major changes to their lives deemed necessary to try to negate the probability of infection with the virus, such as cocooning. It is increasingly clear within Ireland and other countries that long-term residential care homes have become epicentres of the infection. As many of these homes in Ireland cater almost exclusively for dementia patients, or are the residence for many people living with dementia, the ramifications of the Covid for people living with dementia are far reaching.

This is a timely article highlighting how the health system, and broader society, may help this population during this crisis. There will be many research pieces on the provision of medical care to certain population groups forthcoming in the research literature. The straightforward recommendations in this piece also provide some simple changes that could be easily implemented. But these changes or policies are to stimulate the 'person', rather than treat the 'patient', and provide some normalcy to their everyday lives. These points, and the discussion of wider society values on living with vulnerable populations are to be welcomed.

Points to be addressed:

The numbers of cases are changing daily. But as the prevalence of Covid has increased substantially since the time of writing (April 6th), especially in the residential care sector (with over 40% of nursing homes for examples having a Covid case), a greater recognition of this issue and a more updated number on Covid in the opening paragraph is recommended.

Is the rationale for the Open Letter provided in sufficient detail?

Yes

Does the article adequately reference differing views and opinions?

Yes

Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Yes

Is the Open Letter written in accessible language?

Yes

Where applicable, are recommendations and next steps explained clearly for others to follow?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Health Economics. Inequalities. Health System Analysis. Cancer.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 18 May 2020

Eamon O'Shea, National University of Ireland Galway, Galway, Ireland

Thank you for your comments. I have updated case numbers and mortality data.

Competing Interests: None