

Social Care Working Group: Consensus Statement on family or friend visitor policy into care home settings, 2 November 2020

Summary

- Visiting care home residents serves a variety of functions and has recognised benefits to residents in terms of health and wellbeing. It also carries a concurrent theoretical risk of disease ingress to the care home setting from different communities. The nature of benefits and risks may vary by the type of visit.
- There is an absence of evidence regarding the risk of introduction and transmission of infection from visitors. This is partly due to the timing of policy changes in the first wave of the pandemic including early closure of many residential and nursing settings.
- Evidence from a study of medical crisis in older people suggested that isolation has a strong negative impact on quality of life (adapted in Figure 1 below). Weaker evidence from modelling simulations alone, based on assumptions about the nature of contact by visitors relative to staff, suggests that allowing visitors increases cases of COVID-19 in a care home by statistically insignificant numbers, and therefore has very limited negative impact on quantity whilst improving quality of life.
- Policy decisions therefore need to take into consideration not only the scientific evidence about the two sorts of harm – risk of harm from COVID-19 and risk of harm from isolation – but also the views of, and impact on, all of those affected, residents, their loved ones, staff and community.
- To progress this complex discussion on the balance of harm and benefit and the associated evidence base, further work is necessary in order to consider the scope of changes and use of alternative measures of wellbeing. Commissioning new studies will not provide instant results - reporting timescales are likely to be over months. However, appropriate studies can be commenced quickly if adequately funded and conducted by a group with experience in this area and an understanding of the particular sensitivities of working with this population. Design is critical as the timing of studies may affect outputs – for example attitudes may vary with different phases and experience of the pandemic.
- The question of impact of isolation resulting from lockdown also arises in other vulnerable social care groups in slightly different contexts. For example people with learning disabilities, but living at home, have not had day-care access for a number of months and cannot understand a lack (or sudden loss of) meaningful social interaction. These should also be considered.
- There is no existing simple solution to balance quantifiably both harm and benefit to inform policy development.

Background

1. The decision on whether to allow visitors into care homes for older people is complex and was posed to the SCWG in mid-September after initial consideration in June SAGE of advice as part of a dynamic risk assessment of viral ingress risk. Whilst the focus in this paper is on care home settings, the wider impacts of isolation on vulnerable individuals in their own homes and on their carers should not be overlooked.
2. Although not with care home specific populations there is good evidence in the general population of a link between isolation and loneliness and all-cause mortality. Odds ratios (ORs) show an increased likelihood of mortality for social isolation of 1.29 (95% Confidence Interval (CI); 1.06, 1.56), and an increased likelihood of mortality for loneliness of 1.26 (95% CI; 1.04, 1.53)¹.
3. Care homes are mainly closed residential communities in which staff and visitors will predominantly come in from the local community. Older people living in care homes typically have a life expectancy between 12-18 months, though this is highly variable and lower in nursing home settings². In most, around two thirds have a diagnosis of dementia, though this will be much higher in some specialist settings. The social behaviour of individuals who are mobile and living with dementia is likely to be different from other residents and may be an important factor in the transmission of COVID-19 in this setting, as is true for other infections.
4. Visits to residents allow for the continuation of social and family life, direct care and private conversations, and supports safeguarding. For some residents the visitor is essentially equivalent to peripatetic staff who provide specific care; or to care assistants supporting regular employees to do their work in the care home, rather than simply a social visitor for the resident. To decrease infection risks, family visitors may be happy to isolate for sufficient time before visiting, to undergo regular testing and to remain in isolation whilst visits continue to mitigate their risk of introducing infection from the community. The ability and willingness of visitors to adhere to given regulations should therefore also be considered in future. Attitudes of both visitors and residents may be affected by prior experience of COVID-19 outbreaks within the home being visited and may vary with time.
5. This report also does not consider the difference between indoor or outdoor visits and the logistical implementation of visits is outside of the scope of this work. If specific science advice is needed following policy drafting the working group will review this.
6. The decision-problem involves assessing the positive impact of visits against the harm within and beyond care homes. Allowing visits may increase risk of disease ingress and so potentially cause infections and mortality among other residents and staff. Stopping or severely restricting visitors will lead to isolation in residents and for some, the effective withdrawal of some person centred care, thereby harming the health and wellbeing of residents and others, and have adverse effects on next-of-kin/visitors (especially in the case of death of the resident when not being visited).
7. The decision problem needs consideration not only of the scientific evidence about the two sorts of harm – risk of harm from COVID-19 and risk of harm from isolation – but also of the views of those affected – residents (individually and as a community), their loved ones and staff.
8. The care sector is seeking some practical, straightforward, evidence-based support to enable it to work with the communities within its care settings to make very difficult decisions about the trade-off of these risks.

¹ Leigh-Hunt N, Bagguley D, Bash K, et al. An overview of systematic reviews on the public health consequences of social isolation and loneliness. *Public Health*. 2017;152:157-171. doi:10.1016/j.puhe.2017.07.035

² <https://eprints.lse.ac.uk/33895/1/dp2769.pdf>

9. It is important to undertake further research to better understand and represent directly the views of care home residents and their families on the impact of visiting policies. This is not just for current and any future waves of COVID-19, but also to strengthen the evidence base for any future pandemics that will undoubtedly have adverse impacts on vulnerable groups and social care settings.

Methodological considerations

10. The current operational practice in more general settings and for other infectious diseases is to use the quality-adjusted life-year (QALY) so as to maximise health. This conforms with the standard methods of the National Institute for Health and Care Excellence (NICE). NICE has relied upon an explicit set of social value judgements, on which all of its more technical (or objective) work depends. These value judgements were derived from research with the general population and developed with the aim of permitting comparison of outcomes *across* different population subgroups. It is unclear whether value judgements derived from the general population are appropriate when evaluating the trade-off between outcomes *within* a single population (residents and staff of care home populations) whose values are likely to differ from the general population. NICE has stated that:
 - a. Interventions are assessed for cost-effectiveness by comparing the cost against the gain in health outcome.
 - b. The quality-adjusted life-year (QALY) is the best measure of health for the purposes of economic evaluations.
 - c. A QALY should usually have equal weight irrespective of the population or cohort in whom it is calculated.
 - d. Outcome measures, such as level of pain, level of depression etc, should be provided by the relevant individuals affected (generally patients receiving the intervention but in this case residents in care homes, visitors, their families etc.),
 - e. The value tariff (algorithm) - used to assign a single value weight to each combination of different levels on different dimensions of outcomes - is based on the views of a sample of the general population.
11. Furthermore, broader aspects of wellbeing, particularly for care home populations where many residents are approaching the end of life, are also of immense importance. There are a number of established measures of wider wellbeing. These include measures of 'capability' include such as the ICECAP-O or the ICECAP-SCM. An alternative approach is the Adult Social Care Outcomes Toolkit (ASCOT) designed to measure the domains of quality of life affected by social care: <https://www.pssru.ac.uk/ascot/>. Other measures could be used to measure quality of life, some of which have been mapped to the QALY e.g. DemQoL for dementia. The developers of these tools should be consulted for further guidance. However, although often well developed, these measures are less well established as a utility measure than the EQ5D health-related quality of life for the QALY, and NICE does not routinely require them for their decision making on health outcomes.
12. Importantly, the well-established NICE approach is primarily designed to assess the effect of interventions on individual level health conditions which do not impact on others. It is not well adapted to assessing the impact of a disease on others as in this case, where COVID-19 could transmit to residents and staff, with various outcomes in terms of morbidity and further onward transmission. Although NICE has long sought to integrate health and social care outcomes, there is no established methodology for doing this. As a consequence, there is no "off-the-shelf" methodology that can be used to integrate and quantify the range of relevant values and risks (health, wellbeing and onward transmission) to the situation of COVID-19 in closed residential settings (though work may

be underway that can inform such an approach eventually³). Any methodology recommended has these important limitations. It is essential to recognise the need for further work in this complex field.

13. It is recommended that chosen outcomes for the different approaches for any future work should be synthesised in a 'benefit-harm trade off' framework. Within this framework, decision-makers would be provided with information on the different levels of harm (measured using QALYs etc or newly developed metrics.) impacting upon the different stakeholders (residents, visitors, families etc) with the different policies (isolation versus visits etc.).

Evidence to date

14. There is at present an absence of evidence on outbreaks related to or caused by 'social' and family visitors. Policy and practice in this area changed rapidly in wave 1 of the pandemic without systematic data being collected that tracked how the restrictions on visitors were being implemented. As the pandemic develops, proactive investigations may be a good source of evidence, aided by newer data collection. Other reviews are also underway that are looking at the impact of not allowing visitors⁴.
15. Visitor to resident transmission: Simulation modelling suggests that allowing up to 1 visitor per resident per week creates a single additional case on average per outbreak (essentially an artefact of importation increase rather than cross-transmission). However, when full uncertainty is considered the impact of this visitor policy is statistically insignificant [SCWG report, Alicia Rosello, LSHTM]. Similarly analysis looking at ingress specifically with probability theory suggests that only around 3% of simulations would have outbreaks caused by visitors alone [SCWG report, Ian Hall, UoM] (This latter analysis assumes that a day's worth of close contact by staff is equivalent to an hour's contact with visitors in terms of the transmission risk. Assuming less risk of transmission from visitors (because the single hour's contacts may be more socially distanced and less invasive if the visit is not providing care) than the day's interaction with staff would reduce the proportion of simulations with outbreaks caused by visitors though this is also sensitive to assumptions on use and adherence with personal protection equipment and the time horizon of the analysis.)
16. Impact of Isolation: To assess impact of isolation one may combine life-expectancy and utility values generates a plot of expected QALYs. If life was cut short early (either due to infection or isolation), then the expected QALYs quantifies the quality of life that would be foregone. The expected QALY may be calculated by age and sex for the general population, for nursing home and for residential home residents respectively. Current evidence extracted from Health Survey for England data 2003, 2004, 2005, 2006 can be used to calculate background health-related quality of life using EQ-5D-3L data from a large sample of individuals. Attached to the EQ-5D-3L response data is the utility tariff as developed by Dolan et al⁵ which is used in all health technology assessments conducted by NICE. With the caveat that some data are from people not within care homes but recruited from Acute Medical Units, data from the Medical Crises in Older People

³ University of Sheffield: Extending Qaly project: <https://scharr.dept.shef.ac.uk/e-qaly/about-the-project/>

⁴ Verbeek H, Gerritsen DL, Backhaus R, De Boer BS, Koopmans RT, Hamers JP. Allowing visitors back in the nursing home during the COVID-19 crisis – A Dutch national study into first experiences and impact on well-being. *J Am Med Dir Assoc*. Published online 2020. doi:10.1016/j.jamda.2020.06.020.

Adelina Comas-Herrera has a Long Term Care COVID-19 group and they have done a rapid review of visitor impact, now submitted to Age and Ageing

⁵ <https://ideas.repec.org/p/chy/respap/138chedp.html>

(MCOPs) study⁶ can be used to evaluate EQ-5D-3L and ICECAP-O. Then the impact of a period of social isolation on residents of a care home, with the caveat that it assumes that no-one was socially isolated before and everyone is afterwards can be calculated. Further work is needed before this is relied on for policy, but indicates that the harm of extended isolation may outweigh the impact of disease ingress caused solely by visitors given modelling results above.

17. Resident to visitor transmission. There is currently no evidence of transmission from residents to visitors, albeit based on very low availability of evidence due to cessation of visiting early in the pandemic. However, it is entirely plausible that there could, in some circumstances be a risk of visitors acquiring infection from the care home and even seeding this back into the community. The probability and impact of picking up the virus will be differentiated, according to visitors' age, health and connectivity to their community. The impact will of course be potentially very serious for older spouses of people with dementia, but also potentially also for children of residents many of whom will be over 50. In areas of high prevalence, the visitors will also be at high risk within their own community depending on their behaviour. This will make it difficult to establish causal origin. In such circumstances genomic sequencing may help to establish causality. In addition, more routine data is now being collected on visitors, which could be combined with testing datasets. This could also be used in combination with proactive investigations to establish causality.

Possible next steps

18. There are a range of possible future research and evaluation methodological options that could be run concurrently, including:
 - a. Simulation of an illustrative yet realistic care home set up based on current models with a range of policies (No isolation, 1 month cessation following case identification, cessation for duration of outbreak, 6 month total cessation of visitors) using a QALY/EQ-5D-3L approach including the chance of no outbreak in the care home, with the background community prevalence.
 - b. Evaluation of the risk of visiting on COVID-19 transmission given the nature of physical contact, the built environment, mitigations in place and the risk of direct transmission to other residents and staff to the person visited including the use and adherence with personal protective equipment and social distancing behaviours. The specific risk factors and recommendations for managing risk could be identified in conjunction with SAGE Environmental Modelling Group who have already set out principles for environmental transmission and reviewed the risks within a range of other settings. In addition, more in-depth modelling could be carried out in the longer term through research studies such as the NIHR CONTACT trial or through the National Core Study on Transmission.
 - c. Studies to consider the health and wellbeing of residents in care homes and sheltered housing in other age groups and with other risk factors. For example, residents with learning disabilities may pose different evaluation scenarios and challenges - technical analysis of younger residents may demonstrate more quantifiable life years to gain/lose, but possibly also different infection risks from staff due to lower levels of direct or close physical care. Visitors to this group of people may also in most cases be younger and possibly more socially interconnected in their own lives.

⁶ Gladman J, Harwood R, Conroy S, Logan P, Elliott R, Jones R, et al. Medical Crises in Older People. Program Grants Appl Res [Internet]. National Institute for Health Research; 2015 [cited 2020 Oct 6];3:1–410. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK293738/>

- d. Convening a citizen jury, or similar consensus method, to evaluate and decide value judgements to be used. NICE has accessible citizens' juries see <https://www.nice.org.uk/Get-Involved/Citizens-Council>. This jury could review:
 - i. appropriate specific thresholds taking account of the age of the population in care homes;
 - ii. which outcome should be the main focus for the committee (EQ-5D-3L, ICECAP-O and/or ASCOT);
 - iii. if/how health and capability should be balanced and what discount rate should be applied and:
 - iv. the jury could be, or include, a Care Home jury designed to gather views from the key players in these settings. This would include residents and those who can represent them (where mental capacity is lacking), relatives/ friends, the essential visiting professional, staff and provider organisations.
- e. Commissioning studies that directly ask an appropriate sample of care home residents, their families and staff members about their values/preferences on the trade-off between receiving visitors and the risk of COVID-19. This could be split into two studies:
 - i. A quantitative approach to elicit preferences and values of residents, staff and family members related to the trade-off (for themselves and for others in the institution) of visiting vs infection⁷. (e.g. a discrete choice experiment on how much reduction in life expectancy due to COVID-19 they would be willing to sacrifice to enable different amounts or types of visiting)
 - ii. A qualitative study exploring the experiences and preferences of residents, staff and family carers related to the impact of restricting visiting.
- f. Detailed outbreak investigation including genomics to establish route of entry.
- g. Prospective data collection to learn from any opening of visiting in a systematic way. For example, comparison of weekly testing of visitors as for staff to establish ingress risk from wave 2 and beyond as visiting is allowed in various ways.
- h. Seeking further opinions from leading experts in health economics and social care metrics in the UK as an expert subgroup of the working group, possibly leading to structured elicitation methods (such as variants on Delphi exercises).

19. Commissioning new studies will not provide instant results but adequately funded and conducted by a group with experience in this area (and an understanding of the particular sensitivities of working with this population), studies can be convened quickly. Now is the opportune time to do this, as residents already have real experience of many months of isolation and many have experienced the reality of COVID-19 outbreaks. This means they have lived experience of the actual trade-offs to be made. However the studies would need to be designed to consider a range of views (given the impact on families of reduced contact at end of life with loved ones but also their own risk in infection) and furthermore reflect that attitudes can change over time.

⁷ There are a number of complexities: cognitive impairment, the possible need for remote interviewing, and the need to try to capture respondents' views around their personal risk/ benefit values and the risk/benefit values at the institutional level. If a study is commissioned, applicants could be asked to address the following issues in their proposals: i) the most appropriate methodological approach to eliciting values/preferences in this study group, ideally as simple as possible (e.g. a visual analogue scale with just one or two trade-offs is likely better than a complex discrete choice experiment) ii) how best to elicit proxy values/preferences for those with severe cognitive impairment who cannot do so themselves e.g eliciting the values/preferences of their "best interest decision-makers" iii) how they will capture preferences at the individual level vs preferences at the institutional level iv) how they will capture the heterogeneity of responses in the most appropriate way to inform decision-makers

Further key considerations

20. It must be noted that over 70% of care home residents have cognitive impairment⁸. The median Mini Mental State Examination score in a care home is 11/30 (moderate to borderline severe dementia). Discrete choice experiments require high-level abstract thought so a large proportion of the care home population will not be able to participate in such studies. Those who lack capacity in the terms of the Mental Capacity Act will not be able to participate without special ethics approval. It is important not to assume that the results of discrete choice experiments conducted with care home residents with full cognitive capacity will apply to those with cognitive impairment. Methods to elicit the values and preferences of residents with moderate-severe cognitive impairment will need to be considered so that they are not disadvantaged by not having their voice heard (e.g through the use of proxy or best interest decision-makers, and by observing changes in behaviours in the presence and absence of visiting). Capturing opinions about choices will be important, in addition to capturing the best insight into the views of those with dementia. Furthermore, at least some of the negative impact of isolation will accrue to families/relatives of care home residents experiencing isolation.
21. Isolation resulting from lockdown arises in other vulnerable social care groups in slightly different contexts. For example, people with learning disabilities but living at home have not had day care access for a number of months and may be suffering because of a lack (or sudden loss) of meaningful social interaction. These types of situations require better understanding.

⁸ CFASII study found that around 70% have dementia and over 90% have cognitive impairment.

Policy statements of relevance:

England

Department of Health and Social Care. (2020) Policy paper. Adult social care: our COVID-19 winter plan 2020 to 2021. Published 18 September 2020. Available at:

<https://web.archive.org/web/20201020121145/https://www.gov.uk/government/publications/adult-social-care-coronavirus-covid-19-winter-plan-2020-to-2021/adult-social-care-our-covid-19-winter-plan-2020-to-2021> (accessed 20 October 2020).

Department of Health and Social Care. (2020) Guidance. Update on policies for visiting arrangements in care homes. Updated 21 September 2020.

<https://web.archive.org/web/20201014021436/https://www.gov.uk/government/publications/visiting-care-homes-during-coronavirus/update-on-policies-for-visiting-arrangements-in-care-homes> (accessed 14 October 2020).

Wales

Visits to Care Homes Guidance (updated 23 October)

<https://gov.wales/visits-care-homes-guidance-providers>

Scotland

Coronavirus (COVID-19): adult care homes visiting guidance (updated 20 October)

<https://www.gov.scot/publications/coronavirus-covid-19-adult-care-homes-visiting-guidance/>

Northern Ireland

COVID-19: Regional Principles for Visiting in Care Settings in Northern Ireland – published 22 September 2020 and kept under active review. The guidance applies to hospital and care homes as well as other facilities. It has been drawn up to protect patients, residents and staff from COVID-19, while recognising the importance of human contact to health and well-being.

<https://www.health-ni.gov.uk/sites/default/files/publications/health/COVID-19%20REGIONAL%20PRINCIPLES%20FOR%20VISITING%20IN%20CARE%20SETTINGS%20IN%20NORTHERN%20IRELAND%20-%20revised%2022-09-2020%20%28002%29.pdf>

COVID-19: Guidance for Nursing and Residential Care Homes in Northern Ireland - latest version published on 11 September 2020; it is currently being reviewed/updated. The guidance is aimed at Health and Social Care Trusts and registered providers of accommodation for people who need personal or nursing care. In addition, there are also important messages for relatives and friends of those in nursing and residential homes.

<https://www.health-ni.gov.uk/sites/default/files/publications/health/GUIDANCE-NURSING-AND-RESIDENTIAL-CARE-HOMES-IN-NORTHERN-IRELAND-SEPTEMBER-2020.pdf>