

Family visits to care homes: experiences and perspectives on policies and practices during the COVID-19 pandemic

A summary of ongoing UK research

2<sup>nd</sup> March 2021

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#### **Summary**

Care home resident deaths make up around a third of all COVID-19 deaths in the UK. Visits to care homes from family members have been strictly curtailed to prevent COVID-19 transmission. However, visiting has health and wellbeing benefits for residents and visitors. A key issue is to balance the risks of COVID-19 transmission against the benefits of visiting.

The NIHR Policy Research Unit in Older People and Frailty was approached by the Department of Health & Social Care, Public Health England and the Sage Social Care Working Group to carry out research exploring experiences and preferences of care home staff, families and relatives on visiting in the time of the pandemic. It was agreed that a scope of current ongoing research is needed.

We have identified 17 UK-based research studies exploring care home visiting policies and practices from the perspectives of care home staff, relatives and/or residents. The majority of this research is being conducted in England and most studies will report findings from summer 2021 onwards.

Emerging findings highlight that differential impacts of blanket visiting policies are perceived to be particularly unsuitable for the high proportion of residents with cognitive impairment. There is a need to appreciate the role of many family members in providing additional care, and the importance of clear communication between care homes and families.

Although there is some information about experiences of resource issues (e.g. challenges with supply of personal protective equipment (PPE)), detailed perspectives on finance and resource implications of visiting policy and practice (e.g. PPE, visiting pods, on-site testing, secure visiting areas, personalised visiting plans, and the extra administration required) are currently lacking.

The roles of other stakeholders in the health and social care system (e.g. local public health teams, regulators, suppliers of PPE and testing equipment) in the development and implementation of visiting policies and practices are currently unclear.

Some studies will explore perspectives on vaccination and it may be important to review findings of these studies in light of vaccine uptake rates among residents and staff.

The majority of studies with emerging findings have sampled very low numbers of care homes and participants. However, some of the newest studies are working with much larger samples. It is likely that perspectives on the influence of care home characteristics (e.g. non-profit or for-profit, independent or chain, size) on the development and implementation of visiting policies and practice will be forthcoming.

### <u>Key issue</u>

In the UK, approximately 500,000 adults live in care homes,<sup>1,2</sup> with the latest estimates suggesting that care home resident deaths make up a third of all COVID-19 deaths.<sup>3</sup> Since the first nationwide government restrictions were implemented on 24<sup>th</sup> March 2020, visits to care homes from family members have been strictly curtailed. However, visiting has health and wellbeing benefits for residents and visitors. As guidelines and policy on family visiting continue to evolve, there is a need to understand experiences and perspectives of care home staff, families and relatives on balancing the risks of COVID-19 transmission against the benefits of visiting.

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### What is already known?

At the beginning of the pandemic (February – April 2020), a series of rapid expert reviews of evidence and UK policy to produce top tips for practice revealed that there was 'a lot to say about what care homes should do and far less about how they should do it'.<sup>4</sup> It highlighted a risk of information overload for managers and staff who are faced with implementing a raft of rapidly changing policy and guidance with little resource.

In January 2021, the International Long Term Care Policy Network published a review of international guidelines and emerging practice on safe visiting.<sup>5</sup> The main recommendations are that blanket visitor bans should not be used, safe practice should be determined according to local intelligence, family caregivers should be given more frequent hands-on visiting time, care homes should receive additional government funding to implement safe visiting practice, and that visiting practice should be overseen by regulators. This review is comprehensive but little of the research it summarises is from the UK. Recent UK work with 250 care home managers and staff found that around half of their questions at the beginning of the pandemic were related to infection prevention and control, including uncertainties around PPE procurement, isolation of residents and staff, and

<sup>&</sup>lt;sup>1</sup> Bell D et al. 2020: <u>https://ltccovid.org/wp-content/uploads/2020/08/COVID-19-mortality-in-long-term-care-final-Sat-29-1.pdf</u>

<sup>&</sup>lt;sup>2</sup> The term 'care home' refers to long-term care facilities providing 24-hour care (residential homes), some of which include the provision of nursing care (nursing homes).

<sup>&</sup>lt;sup>3</sup> Comas-Herrera A et al. 2020: <u>https://ltccovid.org/wp-</u>

content/uploads/2021/02/LTC COVID 19 international report January-1-February-1-1.pdf

<sup>&</sup>lt;sup>4</sup> Towers A-M et al. Producing 'Top Tips' for Care Home Staff During the COVID-19 Pandemic in England: Rapid Reviews Inform Evidence-Based Practice but Reveal Major Gaps. *Journal of Long-Term Care*, 2020;151-166. <u>http://doi.org/10.31389/jltc.43</u>

<sup>&</sup>lt;sup>5</sup> Low L-F et al. 2021: <u>https://ltccovid.org/wp-content/uploads/2021/01/Care-home-visiting-policies-international-report-19-January-2021-1.pdf</u>

testing.<sup>6</sup> Survey work in May and June 2020 found that care homes reported difficulties in testing residents who may find procedures uncomfortable and distressing, and highlighted a need to develop alternative testing methods.<sup>7</sup> A small qualitative study in the East Midlands of England found perceptions that centrally organised government intervention may have had unintended negative effects, including disruption to PPE supply chains, and a feeling among managers that they were held accountable for following general guidelines inappropriate for their settings.<sup>8</sup>

# February 2021: UK government roadmap

On Monday 22<sup>nd</sup> February 2021, the UK government published the COVID-19 Response – Spring 2021 report, detailing its roadmap to ease COVID restrictions over the coming months.<sup>9</sup> As part of Step 1, from 8<sup>th</sup> March care home residents will be allowed to nominate one named visitor for indoor visits. This visitor will be required to take a lateral flow test on each visit, wear PPE and keep physical contact to a minimum. Other forms of visiting should still be encouraged, including outdoor and screened visits which may include the use of visiting pods or 'window' visits. If a home experiences a COVID-19 outbreak, all visiting should cease, except for residents who have been identified as being at end-of-life.

The report states that care home staff are being tested twice a week, free PPE is being provided to the social care sector until the end of June 2021, and visitors who provide unpaid care (e.g. personal care) to residents will have access to the same testing (Pillar 1) and PPE as staff.

The report also states that 89% of all older adult care home residents have been vaccinated. Data from NHS England show that as of 25<sup>th</sup> February 2021, 69% of care home staff in England have been vaccinated.<sup>10</sup>

# Scope of this briefing

This briefing presents a summary of ongoing UK-based research studies that include collection of data about experiences and perspectives of care home staff, relatives and residents on policies and practices for family visiting. Potential studies were identified through web searches and professional networks. Lead investigators were contacted for further information, including any key interim findings. Studies were included if they had a start date of March 2020 or later and if they are using review, qualitative and/or survey methodology. More detail on the searches is in Appendix 1.

<sup>&</sup>lt;sup>6</sup> Spilsbury K et al. SEeking AnsweRs for Care Homes during the COVID-19 pandemic (COVID SEARCH). *Age and Ageing*, 2020;afaa201. <u>https://doi.org/10.1093/ageing/afaa201</u>

<sup>&</sup>lt;sup>7</sup> Graziadio S et al. Unmet clinical needs for COVID-19 tests in UK health and social care settings. *PLOS ONE*, 2020;15(11):e02421252020. <u>https://doi.org/10.1371/journal.pone.0242125</u>

<sup>&</sup>lt;sup>8</sup> Marshall F et al. Care homes, their communities, and resilience in the face of the COVID-19 pandemic: interim findings from a qualitative study. *BMC Geriatrics*, 2021;21:102. <u>https://doi.org/10.1186/s12877-021-02053-9</u> <sup>9</sup> https://www.gov.uk/government/publications/covid-19-response-spring-2021

<sup>&</sup>lt;sup>10</sup> https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2021/02/COVID-19-weekly-announcedvaccinations-25-February-2021.xlsx

# **Summary of findings**

We identified 17 ongoing UK-based research studies. A table of the studies is provided below, ordered by completion date. A more comprehensive table is provided in Appendix 2, which includes study aims, methodologies, funders, and links to online resources where available.

Study no.	Title	Lead investigator and institution	Start and end dates
1	Understanding COVID-19 testing pathways in English	Dr Massimo Micocci, Imperial College	July 2020 –
	care homes to identify the role of point-of-care	London & NIHR London In Vitro	August 2020
	testing: an interview-based process mapping study	Diagnostics Co-operative	
2	Understanding and reducing the psychosocial impact	Dr George Palattiyil, University of	May 2020 –
	of Coronavirus social distancing and behavioural	Edinburgh	Oct 2020
	changes on families of care home residents in Scotland		
3	LESS COVID-19: Learning by Experience and Supporting	Professor Karen Spilsbury, University of	Jun 2020 -
	the Care Home Sector during the COVID-19 pandemic:	Leeds & NIHR ARC Yorkshire and	Jan 2021
	Key lessons learnt, so far, by frontline care home and	Humber	
	NHS staff		
4	Barriers and facilitators to reducing COVID-19	Dr Diane Bunn, University of East	Nov 2020 –
	transmission in care homes: a qualitative exploration	Anglia	Apr 2021
	and survey (TRAQ)		D 2020
5	Identifying approaches, barriers and facilitators to	Professor Claire Surr, Leeds Beckett	Dec 2020 –
<u> </u>	visiting in care homes during COVID-19	University	Apr 2021
6	The experience of family carers and keeping in regular	Associate Professor Kathryn Hinsliff-	Apr 2020 –
	contact with loved ones who permanently live in a	Smith, De Montford University	ongoing
	care home during the COVID-19 Pandemic: A UK		(potentially
7	perspective The effect of COVID-19 related care home closures on	Dr Clarissa Giebel, University of	12 months) Oct 2020 –
/	family members, residents, and staff	Liverpool & NIHR ARC North West	Jun 2021
	Tariniy members, residents, and star	Coast	JUII 2021
8	Care Homes and Coronavirus: Exploring the impact of	Ms Kath Wilkinson, University of Exeter	Nov 2020 –
-	the COVID-19 pandemic on the emotional wellbeing of	& NIHR ARC South West Peninsular	Jul 2021
	care home practitioners		
9	Impact of the COVID-19 pandemic on care home	Professor Jo Knight, Lancaster	Aug 2020 –
	pathways, outcomes and safety of care	University	Aug 2021
10	Examining the health and social care workers' mental	Dr Paula McFadden, Ulster University	May 2020 –
	wellbeing and quality of working life during COVID-19		Oct 2021
	(Health and Social Care Workforce Research Study)		
11	Protecting older people living in care homes from	Dr Joanne Fitzpatrick, King's College	Nov 2020 –
	COVID-19: challenges and solutions to implementing	London	Oct 2021
	social distancing and isolation		
12	Ensuring respect for human rights in locked down care	Professor Wayne Martin, University of	Nov 2020 –
	homes	Essex	Nov 2021
13	Rapid evaluation of the care home response to the	Dr Katherine Sleeman & Dr Catherine	Jan 2021 –
	need for palliative and end-of-life care during the	Evans, Cicely Saunders Institute, King's	Dec 2021
	COVID-19 pandemic: integration, communication and	College London	
	workforce resilience (CovPall_CareHome)		
14	Culture Box: using multisensory Culture Boxes to	Professor Victoria Tischler, University	Jun 2020 –
	promote public health and to support wellbeing of	of Exeter	Dec 2021
	people with dementia in care homes		
15	UndersTanding the distinct challenges for Nurses in	Dr Diane Bunn, University of East	Feb 2021 –
	Care Homes: LeaRnIng from CoVid-19 to support	Anglia	Jan 2022
	resiliencE and mental wellbeing (THRIVE)		
16	VIVALDI study (COVID-19 in care homes)	Dr Laura Shallcross, University College	May 2020 –
		London	Apr 2022
17	Understanding the factors that shape care homes'	Ms Josie Dixon, London School of	Jan 2021 –
	responses to Government COVID-19 guidance on	Economics and Political Science	Apr 2022
	visiting arrangements		

All studies explore experiences and perspectives of care professionals [1-17]. Seven studies also involve relatives [2, 5-7, 11, 14, 17]. One study aims to involve residents directly [11]. The majority of studies anticipate being able to start reporting findings from summer 2021 onwards. All studies are externally funded apart from two [5, 6]. No evaluation of study quality was undertaken of studies included in this review.

#### Differential impact of visiting restrictions and challenges to human rights

Several studies highlight the differential impact of visiting restrictions, particularly for residents with cognitive impairment, which is perceived to be at odds with human rights. One study in Scotland found widespread concerns that the human right to family life has not been adequately balanced against risk of infection, and reported that experiences of visiting restrictions have shown a lack of value placed by society on certain groups, particularly people with dementia and minority ethnic communities [2]. Another study is explicitly addressing human rights, with the blanket visiting ban being one of its three main topics of focus [12]. This study does not have any emerging findings to report at present, but expects findings to become available over summer 2021.

Residents with cognitive impairment may be unable to engage in, less able to benefit from and may become distressed by, socially distanced or remote visiting [5]. They may be confused by visiting restrictions [9], find PPE challenging to understand [3] and overall there is a greater demand on staff resources to support residents with cognitive impairment to have a visit than more cognitively intact residents [5]. Alongside these challenges, respondents indicate that residents with cognitive impairment may also be likely to decline more quickly in the absence of visits, particularly those who are used to receiving several visits a week [2, 3, 8]. This may be surprising and difficult for families to witness when visiting is permitted again, and families may need support to process and understand this [3]. Care home staff may have felt the emotional toll of managing family emotions and making up for the lack of in-person visits [9]. A survey of 444 family carers found that 76% gave responses indicating mental distress, with women scoring higher than men and partners of residents scoring higher than children [2].

Managers should be able to discuss and encourage indoor visits where possible for those who would otherwise be severely affected by the absence of such visits [2]. However, the layout of the home can often determine what may or may not be possible [2, 3, 5]. (This is also the case for alternative forms of visiting, as 'window visits' may not be available for residents on higher floors [2, 5].) Following the announcement on 22<sup>nd</sup> February that one indoor visitor per resident will be permitted, one study [5] intends to include questions about how families will decide who visits, how care homes will manage scenarios in which families cannot agree upon the designated visitor, when care homes for visiting to accommodate in-person visiting with testing and PPE.

#### PPE and testing

The Health and Social Care Workforce Study [10], collecting data from all four devolved nations, has reported that provision of PPE has been sporadic and rationed, with some staff having to purchase their own. Recommendations for obtaining and sustaining supplies of PPE include the need for regular review by the sector regulator. The LESS COVID-19 study [3] has reported experiences of inflated costs of PPE at the beginning of the pandemic, and a perception among care home staff that the NHS was prioritised, with staff sometimes unfavourably contrasted the PPE they were wearing with that worn by staff in intensive care units or by visiting paramedics. Care home management have a key role in promoting confidence in PPE and infection control practice [3]. Staff may also experience frustration if they perceive a lack of compliance from relatives regarding PPE, social distancing and avoiding touch [2]. As social care workers, care home staff are members of the occupational group who are the most likely to have caring responsibilities of their own outside of work, and are likely to have concerns about contracting infection themselves [10].

Resources to monitor changing guidance and implement new practice may not be feasible for many homes [5]. The policy on visiting with rapid testing has been perceived as an unworkable burden for some homes [9]. A small qualitative study, as part of the larger CONDOR programme of research evaluating new testing methods, has found that testing in care homes is complex and requires reconfiguration of staffing and environment [1]. Isolation and testing procedures are challenged when providing person-centred care to people with dementia. Point-of-care testing results could give care homes greater flexibility to test in person-centred ways. However, care home staff may interpret testing guidance, rather than follow it verbatim. Any point-of-care testing approach needs to be evaluated in the specific context of care homes to understand its effect on care home processes [1].

#### Appreciating the role of family members

Relatives are often crucial providers of care. This may be recognised by individual care homes [6], but there is evidence to suggest that—at least prior to the government announcement on 22<sup>nd</sup> February—policymakers have been slow to recognise this role; the very term 'visitor' may be felt by some relatives to epitomise this lack of recognition [2]. Relatives appeared to initially understand and accept visit restrictions, but some have become distressed and frustrated at the lack of clear guidelines, and may perceive alternative options such as short-duration window or pod visits as inadequate [2, 6]. This frustration may have been amplified when seeing other sectors in society reopening [2]. The variety of different approaches and changes to visiting practices may be confusing and distressing for relatives [5]. Staff opinions about outdoor and screened visits may be more positive than relatives [4].

#### Maintaining communication

Prior trust and clear communication between families and care homes is really important if visiting is to be restricted and good practice cannot be seen in action, as relatives may feel excluded and concerned about resident wellbeing [2, 7]. Virtual communication should now be standard practice

[2], but may not be appropriate for some residents with cognitive impairment and there are mixed views on its ethical status at end-of-life [3]. Exceptions to visiting restrictions for residents who are at end-of-life may be difficult to implement as it is not clear when people with dementia may be considered at end-of-life [5]. Suggestions have included the role of a family liaison officer to support families at end-of-life [3]; more work is underway to understand perspectives on visiting in this scenario [13].

### Current research gaps

The extent of **finance and resource implications** for care homes implementing visiting policies (e.g. through use of PPE, visiting pods, on-site testing, secure visiting areas, personalised visiting plans, and the extra administration required) is currently not clear. Finances and resources may be explored in ongoing studies through broader questions about implementation and workability of policies **[1, 5, 7, 9, 10, 11, 13, 17]**. The government's COVID-19 Response – Spring 2021 report highlights the financial support that has been given to the adult social care sector, including free PPE which is now being provided until the end of June 2021. However, given the implications of the general under-resourcing of the care home sector for practice during the pandemic—as highlighted by the evidence reviews undertaken at the beginning of the pandemic<sup>5</sup>—research that focuses explicitly on the finance and resource implications of implementing visiting policies may be urgently required.

Relatedly, the **roles of other stakeholders in the health and social care system** (e.g. local public health teams, regulators, suppliers of PPE and testing equipment) in the development and implementation of visiting policies and practices are currently unclear. Some ongoing research includes a focus on the role of other stakeholders [5, 9, 11, 13, 17]. However, further explicit work in this area may be warranted, particularly with regard to regulation and governance, and procurement and implementation of PPE and testing.

Given the timing, to date there has been no exploration of perspectives on **vaccination**. This issue is likely to be explored in some studies as the vaccination programme continues to be rolled out [5, 7, 13, 16, 17]. It may be important to review findings of these studies in light of vaccine uptake rates among residents and staff.

Finally, perspectives on the influence of **care home characteristics** (e.g. non-profit or for-profit, independent or chain, size) on the development and implementation of visiting policies and practice are lacking. Findings from English national care home data show that larger care homes have been more likely to experience excess mortality during the pandemic.<sup>11</sup> The majority of studies we found with emerging findings have sampled very low numbers of care homes and participants. However, some of the newest studies are working with much larger samples **[13, 14, 16, 17]**, therefore it is likely that experiences and perspectives relating to care home characteristics will be forthcoming.

<sup>&</sup>lt;sup>11</sup> Morciano M et al. Excess mortality for care home residents during the first 23 weeks of the COVID-19 pandemic in England: a national cohort study. *Pre-print, not peer reviewed*. https://doi.org/10.1101/2020.11.11.20229815



### **Limitations**

Care home visiting during the COVID-19 pandemic continues to be a fast-changing landscape. This briefing was produced following a rapid search conducted in early February 2021 for relevant UK-based academic research that has not yet reported findings in peer-reviewed journals. It does not include other work that may be in progress, such as local audit or evaluation. The quality of the ongoing research highlighted in this briefing is not clear and has not been formally evaluated as part of this briefing.



### **Appendix 1: Searches**

Studies were identified from searches of the following databases and websites:

- International Long Term Care Policy Network (LTCcovid resource): <a href="https://ltccovid.org/completed-or-ongoing-research-projects-on-covid-19-and-long-term-care/">https://ltccovid.org/completed-or-ongoing-research-projects-on-covid-19-and-long-term-care/</a>
- NIHR Policy Research Programme: <u>https://www.nihr.ac.uk/documents/policy-research-programme-covid-19-research/24757</u>
- NIHR Urgent Public Health: <u>https://www.nihr.ac.uk/covid-studies/</u>
- NIHR ENRICH: <u>https://enrich.nihr.ac.uk/projects/</u>
- EPPI-Centre COVID-19 'living' systematic map of research: <u>https://eppi.ioe.ac.uk/cms/</u>
- ESRC: <u>https://esrc.ukri.org/files/news-events-and-publications/news/esrc-covid-19-activity/</u>
- Wellcome: <u>https://wellcome.org/what-we-do/our-work/covid-19-research-weve-funded</u>
- UK Research and Innovation (UKRI): <u>https://www.ukri.org/wp-</u> content/uploads/2020/12/UKRI-101220-COVID-19-Research-List-WEB.xlsx
- Health Foundation: <u>https://www.health.org.uk/funding-and-</u> partnerships/programmes/covid-19-research-programme
- THIS Institute: <u>https://www.thisinstitute.cam.ac.uk/projects/</u>
- UK Collaborative on Developmental Research: <u>https://www.ukcdr.org.uk/covid-circle/covid-19-research-project-tracker/</u>
- Alzheimer's Society: <u>https://www.alzheimers.org.uk/research/our-research/research-projects/current-projects</u>

The following pre-print sites were also searched:

- Open Archive of the Social Sciences: <u>https://osf.io/preprints/socarxiv</u>
- Med Archive: <u>https://www.medrxiv.org/</u>
- F1000Research: <u>https://f1000research.com/</u>

Publicly-available study information was gathered from webpages where possible. Lead investigators were contacted with a request to provide information about their study, including start and end dates, a protocol or summary of the study remit, any key messages that may be shared now, and when they expect findings to be available.

Members of the NIHR Applied Research Collaboration (ARC) Care Homes Research Network were also contacted if they had not already been identified as lead investigators from other searches.



### Appendix 2: Ongoing studies

Ongoing UK-based academic research studies relevant to perspectives on care home visiting policies and practices. Studies are listed in order of completion date, soonest first.

Study	Title and main aim(s); website/online information where available	Lead investigator and institution	Funder	Methodology summary	Start and end dates	Status as of February 2021	Date findings
<u>no.</u> 1	Information where availableUnderstanding COVID-19 testing pathways in English care homes to identify the role of point-of-care testing: an interview-based process mapping studyThis study evaluates current testing pathways in care homes to understand how testing strategies have been implemented in care homes, how these strategies influence the testing and management of residents and the degree of readiness in care homes for implementation of point-of-care testing.	Dr Massimo Micocci, Imperial College London & NIHR London In Vitro Diagnostics Co-operative	UK Research and Innovation (UKRI), Asthma UK and the British Lung Foundation, as a part of the CONDOR study	Semi-structured interviews with n=10 staff from n=8 care homes	July 2020 – August 2020	February 2021 Completed; part of the CONDOR platform of studies evaluating new COVID-19 diagnostics in the settings they will be used	expected Pre-print published November 2020, awaiting peer review
	Pre-print, not yet peer-reviewed: <u>https://doi.org/10.1101/2020.11.02.2022455</u> <u>0</u> This study is part of the CONDOR platform of studies: <u>https://www.condor-</u> platform.org/condor_workstreams/condor-ch						
2	Understanding and reducing the psychosocial impact of Coronavirus social distancing and behavioural changes on families of care home residents in Scotland To examine the impact of care home lockdown and social distancing to minimise	Dr George Palattiyil, University of Edinburgh	Chief Scientist Office, Scottish Government	Interviews with family carers (n=36) and senior stakeholders (n=19); online survey of family carers using the General Health Questionnaire (n=444)	May 2020 – Oct 2020	Disseminating findings and drafting manuscripts for publication	Reports available – see website



	threats of COVID-19 on the health and well- being of family carers and investigated how care home staff helped relatives to stay in touch with care home residents. Information and findings: <u>https://www.creativecovidcare.com/</u>						
3	LESS COVID-19: Learning by Experience and Supporting the Care Home Sector during the COVID-19 pandemic: Key lessons learnt, so far, by frontline care home and NHS staff To capture the experiences of frontline care home and NHS staff caring for older people with COVID-19 and to share the lessons learnt about the presentation, trajectories, and management of the infection with care homes that have and have not yet experienced the virus.	Professor Karen Spilsbury, University of Leeds & NIHR ARC Yorkshire and Humber	Dunhill Medical Trust	Appreciative approach: interviews with frontline staff (n=18 care home staff, n=17 NHS staff); consultation event with senior operational and quality managers (n=11) in care homes	Jun 2020 - Jan 2021	Completed; report to remain an active document that can be updated via online feedback	Report available – see website
	Report available: <u>https://www.nationalcareforum.org.uk/wp-</u> <u>content/uploads/2020/10/LESS-COVID-19-</u> v2.pdf						
4	Barriers and facilitators to reducing COVID- 19 transmission in care homes: a qualitative exploration and survey (TRAQ) To extend our awareness of how care home staff are coping with infection control mitigation measures, so that we can identify issues facing care home workers and managers in delivering the safest possible care to their residents during the COVID-19 crisis and the challenges these may pose.	Dr Diane Bunn, University of East Anglia	NIHR Health Protection Research Unit in Emergency Preparedness	Online survey; key informant interviews	Nov 2020 – Apr 2021	Data collection complete, analysis ongoing	April 2021



5	Identifying approaches, barriers and facilitators to visiting in care homes during COVID-19To explore current visiting practices for relatives of care home residents with dementia across England, best practice approaches and barriers and facilitators to implementing these.https://padlet.com/CentreForDementiaResea rch/xptuxjoyvybkgevg	Professor Claire Surr, Leeds Beckett University	Internally funded by Leeds Beckett University	Rapid literature and practice review; national online survey (relatives and care home providers/managers); interviews (n=10 relatives; n=10 senior staff)	Dec 2020 – Apr 2021	Review complete; survey and interviews about to begin	May 2021
6	The experience of family carers and keeping in regular contact with loved ones who permanently live in a care home during the COVID-19 Pandemic: A UK perspective   To explore the experiences for family who are unable to visit their relatives who permanently reside in a care home. This relates to 'usual' family visits as well as compassionate visits that may be made at a time when end-of-life procedures would be followed.   https://www.dmu.ac.uk/research/centres-institutes/ihhpsc/project-information.aspx	Associate Professor Kathryn Hinsliff- Smith, De Montford University	Internally funded by De Montford University	Qualitative interviews with family carers (n=15); rapid review of global evidence for best practice of communication methods employed within long-term residential homes	Apr 2020 – ongoing (potentially 12 months)	Interview analysis underway. Preliminary findings disseminated in June 2020 and February 2021. Rapid review write up in progress (11 papers included)	June 2021 onwards
7	The effect of COVID-19 related care home closures on family members, residents, and staff To develop a thorough understanding of how COVID-19 has impacted on the lives of family members and residents, and how staff have to adapt to providing care.	Dr Clarissa Giebel, University of Liverpool & NIHR ARC North West Coast	NIHR ARC NWC and The Geoffrey and Pauline Martin Trust	Baseline interviews with care home staff (n=16) and family carers (n=26) of people with dementia living in care homes; follow-up interviews about how vaccination and increased testing has potentially changed care provision and visiting	Oct 2020 – Jun 2021	Baseline interviews complete, first paper submitted for peer review. Follow-up interviews about to begin	March 2021 onwards

8	Care Homes and Coronavirus: Exploring the impact of the COVID-19 pandemic on the emotional wellbeing of care home practitioners	Ms Kath Wilkinson, University of Exeter & NIHR ARC South West Peninsular	Alzheimer's Society and Dunhill Medical Trust	Interviews with care home owners, managers and staff	Nov 2020 – Jul 2021	Ongoing	July 2021
	To understand the impact of the COVID-19 pandemic on people working in care homes in England. We would like to explore and learn about how the pandemic has impacted on the emotional wellbeing of staff, including what is being done and could be done to try and protect and support wellbeing.						
	Part of the broader Exeter University, Care Homes and Knowledge (ExCHANGE) Collaboration: <u>https://arc-</u> <u>swp.nihr.ac.uk/research/projects/the-</u> <u>exchange-collaboration/</u>						
9	Impact of the COVID-19 pandemic on care home pathways, outcomes and safety of care To evaluate the impact of the pandemic on health service provision and outcomes and provide evidence required to inform the future effective, safe management of care home residents.	Professor Jo Knight, Lancaster University	Medical Research Council, as part of the UKRI Rapid Response Initiative	Analysis of linked care home, community, Emergency Department and hospital admissions data from the North East (n=68 homes, >2500 residents) from before, during and after easing the lockdown period; interviews with staff from a range of care homes and community clinical teams	Aug 2020 – Aug 2021	Data collection underway	August 2021
	http://www.research.lancs.ac.uk/portal/en/u pmprojects/dsicovidimpact-of-covid19- pandemic-on-care-home-pathways- outcomes-and-safety-of-care(f07e7f46-2863- 4735-bc85-981b01e46818).html						

10	Examining the health and social care workers' mental wellbeing and quality of working life during COVID-19 (Health and Social Care Workforce Research Study) To explore the perspectives of nurses, midwives, allied health professionals, social care workers and social workers in relation to the challenges they are facing whilst working in health and social care during COVID-19. We are focusing primarily on the mental wellbeing and the quality of working life of these occupational groups, exploring what coping strategies and employer supports have worked or not worked for them and what could be improved.	Dr Paula McFadden, Ulster University	Northern Ireland Social Care Council; Southern Health and Social Care Trust; NIHR PRU in Health & Social Care Workforce (King's College London); Public Health Agency HSC R&D Division	Participants from all four devolved UK regions. Surveys (validated scales assessing wellbeing, work- related quality of life and coping strategies, and open-ended questions about experiences) carried out at three time points: May – July 2020 (n=3290 responses, <b>13.3% care home staff</b> ); November 2020 – January 2021; May – July 2021. Two focus group rounds: December 2020 - January 2021; June 2021	May 2020 – Oct 2021	Two surveys and one focus group round complete. Currently recruiting for second focus group	Findings from first survey available now (see project website – to be updated regularly as findings are available)
11	Protecting older people living in care homes from COVID-19: challenges and solutions to implementing social distancing and isolation To explore and understand the real-life experiences of implementing social distancing and isolation of residents in care homes for older people from the perspective of residents, families/friends, staff working in and with care homes, and to develop a toolkit of resources for health and care delivery now and for any future outbreaks. https://fundingawards.nihr.ac.uk/award/NIH R132541	Dr Joanne Fitzpatrick, King's College London	NIHR Health Services Delivery & Research Programme	Phase 1: rapid review of evidence; Phase 2: case studies with care homes in England (n=6): interviews with care home staff/residents and families/friends (n=5/3/3 in each home), review of local policies and protocols related to managing social distancing and isolation of residents and routine care home data, focus group with external stakeholders (n=8)	Nov 2020 – Oct 2021	Conducting rapid review and recruiting care homes	August 2021
12	Ensuring respect for human rights in locked down care homes	Professor Wayne Martin, University of Essex	Arts & Humanities Research	Support to public bodies; survey and qualitative interviews with frontline professionals working in	Nov 2020 – Nov 2021	Delivered webinars to frontline	Survey: March 2021; Human rights analysis:

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	This project focuses on three practices that have been reported in care homes during the pandemic: (1) the use of blanket restrictions on the movements of residents and their visitors; (2) the blanket use of "Do Not Attempt Cardio-Pulmonary Resuscitation" (DNACPR) orders; and (3) decisions to restrict transfer of unwell patients to acute-care hospital facilities. The project addresses two main questions. First, how should the human rights to (inter alia) life, liberty, and non- discrimination be interpreted and applied to these three practices in the context of a public health emergency? Second, how can existing roles such as best-interests assessors (BIAs) and independent mental capacity advocates (IMCAs) best be adapted to help ensure respect for the human rights of residents who are living and dying in locked- down care homes? Part of the Essex Autonomy Project: https://autonomy.essex.ac.uk/		Council under the UKRI COVID-19 Rapid Response funding scheme	and around care homes; development of training materials		professionals and provided support to a regional NHS Ethics Committee. Currently piloting survey and training materials	June 2021; Training curriculum: September 2021
13	Rapid evaluation of the care home response to the need for palliative and end-of-life care during the COVID-19 pandemic: integration, communication and workforce resilience (CovPall_CareHome) To examine the response of care homes in England to meet the rapidly increasing need for palliative and end-of-life care for residents during the COVID-19 pandemic, and make recommendations for policy.	Dr Katherine Sleeman & Dr Catherine Evans, Cicely Saunders Institute, King's College London	NIHR Policy Research Programme	Online survey with care homes (n=400); in-depth case studies with care homes (n=20-24): interviews with managers or clinical leads	Jan 2021 – Dec 2021	Set up	July 2021 onwards



14	Culture Box: using multisensory Culture Boxes to promote public health and to support wellbeing of people with dementia in care homes.	Professor Victoria Tischler, University of Exeter	Arts & Humanities Research Council	Participatory action research; n=40 care homes across UK	Jun 2020 – Dec 2021	Recruitment completed January 2021. Intervention delivery	January 2022
	Nascent evidence indicates that social isolation, loneliness and responsive behaviours have been increasing for care home residents during the COVID-19 pandemic. This research will address these critical issues by producing, distributing and evaluating CV-19 Culture Boxes incorporating public health guidance with creative activities to support health and wellbeing and alleviate social isolation, loneliness and responsive behaviours for people with dementia in care					underway and data collection in progress	
	homes.						
15	UndersTanding the distinct challenges for Nurses in Care Homes: LeaRnIng from CoVid- 19 to support resiliencE and mental wellbeing (THRIVE)	Dr Diane Bunn, University of East Anglia	Burdett Trust for Nursing	Interviews with NMC-registered nurses; workshops	Feb 2021 – Jan 2022	Under ethics review	Interview data: autumn 2021; full findings: spring 2022
	To understand Nursing and Midwifery Council (NMC)-registered nurses' experiences of working in care homes during the COVID-19 pandemic, how this impacts on resilience, mental health and wellbeing, and to collaboratively develop targeted strategies to aid ongoing support.						
16	VIVALDI study (COVID-19 in care homes) In England, official statistics suggest that at least 25% of all deaths in care home residents since the start of pandemic are linked to coronavirus disease 2019 (COVID-19), but limited testing for SARS-CoV-2 early in the	Dr Laura Shallcross, University College London	Department of Health & Social Care	Aiming to recruit 6,500 staff and 5000 residents from 105 care homes across England. Successive rounds of testing for infection will be performed over a period of 12 months. Qualitative interviews with care home staff will	May 2020 – Apr 2022	Recruitment and data collection ongoing	Interview findings: March 2021

	pandemic means estimates of the true burden of disease are lacking. Additionally, little is known about patterns of transmission between care homes, the community and hospitals, or the relationship between infection and immunity in care home staff and residents. The VIVALDI study plans to address these questions.			investigate the impact of the pandemic on ways of working and how test results influence infection control practices and behaviours			
17	-232Understanding the factors that shape care homes' responses to Government COVID-19 guidance on visiting arrangementsTo explore: how care homes have applied the guidance to develop their policies; how personalisation, encouraged in the guidance, is reflected in policies; what help, other than the guidance, care homes have used or needed; whether managers and staff think their policies are workable, acceptable and fair; what consultation has been carried out with residents, families and others, and how this has influenced policies; how policies are communicated, how well this has worked and why; whether family members find policies understandable, fair and proportionate, and why; the most important factors that influence all of the above.https://fundingawards.nihr.ac.uk/award/NIH R202482	Ms Josie Dixon, London School of Economics and Political Science	NIHR Policy Research Programme - Recovery, Renewal, Reset	Stage 1: semi-structured online/telephone questionnaire with care home managers and senior staff & review of policies of care homes (n=200); Stage 2: in- depth interviews with managers and senior staff (n=20 homes); Stage 3: interviews with family carers (n=30)	Jan 2021 – Apr 2022	Stage 1 questionnaire going live	Stage 1 questionnaire results anticipated mid- summer 2021

This document is available in large print.

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# **Front Cover Image**

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