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

A summary of ongoing UK research (March 2021)

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Background

- In the UK, approximately 500,000 adults live in care homes

- Care home resident deaths make up a third of all COVID-19 deaths

- Following the first nationwide government restrictions implemented on 24th March 2020, visits to care homes from family members were strictly curtailed. Visiting policies and guidance has continued to change since

- At the beginning of 2021, 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 residents on visiting in the time of the pandemic.

- It was agreed that a rapid scope of current, ongoing research was needed.

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What did we already know in early 2021?

- NIHR Applied Research Collaboration (ARC) East of England and cross-ARC care home research collaboration: series of eight rapid expert reviews of evidence and UK policy to produce top tips for practice [1].

- 'A lot to say about what care homes should do and far less about how they should do it'

- Highlighted risk of information overload for managers and staff faced with implementing a raft of rapidly changing policy and guidance with little resource.

[1] Towers et al. 2020: http://doi.org/10.31389/jltc.43

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What did we already know in early 2021?

- January 2021: International Long Term Care Policy Network review of international guidelines and emerging practice on safe visiting [2].
- Main recommendations:
    - 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
    - visiting practice should be overseen by regulators
- Most of this work was not from the UK

[2] Low L-F et al. 2021: https://ltccovid.org/wp-content/uploads/2021/01/Care-home-visiting-policies-international-report-19-January-2021-1.pdf

Our approach

- Potential studies identified through web searches and professional networks

- Lead investigators contacted for further information, including any key interim findings

- Studies included if start date of March 2020 or later and if using review, qualitative and/or survey methodology

- Studies not yet published in peer-reviewed papers; studies in progress or funded and soon to start

- Limitations: rapid search February 2021; local audit or evaluation not included; no quality assessment

Resources searched

- International Long Term Care Policy Network (LTCcovid resource)

- NIHR Policy Research Programme

- NIHR Urgent Public Health

- NIHR ENRICH

- EPPI-Centre COVID-19 'living' systematic map of research

- ESRC

- Wellcome

- UK Research and Innovation (UKRI)

- Health Foundation

- THIS Institute

- UK Collaborative on Developmental Research

- Alzheimer's Society

Pre-print sites:
- Open Archive of the Social Sciences
- Med Archive
- F1000Research

Findings

- Identified 17 ongoing UK-based studies

- All studies exploring experiences of staff

- Seven studies also involving relatives

- One study aiming to involve residents directly

- 15/17 studies externally funded

Project	Lead	Dates
Understanding COVID-19 testing pathways in English care homes to identify the role of point-of-care testing: an interview-based process mapping study	Dr Massimo Micocci, Imperial College London & NIHR London In Vitro Diagnostics Co-operative	July 2020 – August 2020
Understanding and reducing the psychosocial impact of Coronavirus social distancing and behavioural changes on families of care home residents in Scotland	Dr George Palattiyil, University of Edinburgh	May 2020 – Oct 2020
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	Professor Karen Spilsbury, University of Leeds & NIHR ARC Yorkshire and Humber	Jun 2020 - Jan 2021
Barriers and facilitators to reducing COVID-19 transmission in care homes: a qualitative exploration and survey (TRAQ)	Dr Diane Bunn, University of East Anglia	Nov 2020 – Apr 2021
Identifying approaches, barriers and facilitators to visiting in care homes during COVID-19	Professor Claire Surr, Leeds Beckett University	Dec 2020 – Apr 2021
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	Associate Professor Kathryn Hinsliff-Smith, De Montfort University	Apr 2020 – ongoing (potentially 12 months)
The effect of COVID-19 related care home closures on family members, residents, and staff	Dr Clarissa Giebel, University of Liverpool & NIHR ARC North West Coast	Oct 2020 – Jun 2021
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	Nov 2020 – Jul 2021
Impact of the COVID-19 pandemic on care home pathways, outcomes and safety of care	Professor Jo Knight, Lancaster University	Aug 2020 – Aug 2021

Project	Lead	Dates
Examining the health and social care workers' mental wellbeing and quality of working life during COVID-19 (Health and Social Care Workforce Research Study)	Dr Paula McFadden, Ulster University	May 2020 – Oct 2021
Protecting older people living in care homes from COVID-19: challenges and solutions to implementing social distancing and isolation	Dr Joanne Fitzpatrick, King's College London	Nov 2020 – Oct 2021
Ensuring respect for human rights in locked down care homes	Professor Wayne Martin, University of Essex	Nov 2020 – Nov 2021
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)	Dr Katherine Sleeman & Dr Catherine Evans, Cicely Saunders Institute, King's College London	Jan 2021 – Dec 2021
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	Jun 2020 – Dec 2021
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	Feb 2021 – Jan 2022
VIVALDI study (COVID-19 in care homes)	Dr Laura Shallcross, University College London	May 2020 – Apr 2022
Understanding the factors that shape care homes' responses to Government COVID-19 guidance on visiting arrangements	Ms Josie Dixon, London School of Economics and Political Science	Jan 2021 – Apr 2022

Differential impact of visiting restrictions

- Concerns that the human right to family life has not been adequately balanced against risk of infection.

- Experiences of visiting restrictions have shown a lack of value placed by society on certain groups

- 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.

- May also be likely to decline more quickly in the absence of visits. Families may need support to process and understand this

- Layout of home may determine what visiting options are possible (e.g. only residents on ground floor can have 'window' visits?)

PPE and testing

- PPE provision sporadic and rationed

- Inflated costs of PPE at start

- Perceptions that NHS was prioritised

- Frustration if relatives do not comply with PPE guidance

- Care home staff more likely to have caring responsibilities of their own outside of work

- Resources to monitor changing guidance and implement new practice may not be feasible

- Policy on visiting with rapid testing may be burdensome for homes to implement

Role of relatives and communication

- 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 (short-duration window or pod visits) as inadequate.

- Frustration may be amplified by other sectors of society opening up

- Trust and clear communication between homes and families vital

- Virtual communication should now be standard practice

- End of life communication being explored further

Research gaps

- Finance and resource implications: may be explored by studies looking at implementation more broadly but explicit work may be needed

- Role of other stakeholders (e.g. regulation and governance, procurement of PPE etc)

- Perspectives on vaccination – not explored given the timing

- Influence of care home characteristics – most studies sampled low numbers of homes and participants but newer studies are larger

Thank you

- International Long Term Care Policy Network – LTCcovid
- Lead investigators for prompt responses

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