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PROUD TO BE MORE

***Study: 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
July 2020***

P R O U D T O B E M O R E

Aims for this WEBINAR

- Provide an overview of long term care homes in the UK with a focus to the COVID-19 pandemic
- Overview of the UK wide family carers study
- Discuss preliminary findings of the study highlighting potential impacts of COVID restrictions and suggestions going forward

The UK context – our ageing population

- **The UK, like many developed countries has an ageing population with more people living longer lives than previously.**
- **There are now over 15.5 million people aged 60 or over, making up 23% of the UK population.**
- **The number of “older” old people is also rising – there are now 3.2 million people aged 80 or over, and almost 600,000 of these are aged 90 or over.**
- **The largest increases in population growth are likely to come in the older age groups; by 2041 it is expected that there will be over 3 million people aged 85 or over – more than double the number that there are today.**

Source: ONS

The care home sector in the UK

- **In the UK around 450,000 people live in long term residential and nursing homes (Laing & Buisson, 2010).**
- **This is a bed base three times that of the acute hospital sector in England (Ewbank et al., 2020).**
- **Most are aged over 80, many with a cognitive impairment including dementia related conditions as well as multiple co-morbidities (Gordon et al., 2014).**
- **The UK Alzheimer's Society (2016) recently estimated that 70% of care home residents live with dementia or severe memory problems and 1 in 14 people over the age of 65 (7%) and 1 in 6 people over the age of 80 have dementia (17%) (Alzheimer's Research UK, 2019; Alzheimer's Society, 2019b).**

The care home sector in the UK contd..

- **In the UK our care home provision is now predominately privately owned, operated by companies or individuals, chains of care homes, charities/religious organisations and a few operated by a local public authority**
- **Care homes in the UK are funded entirely differently from the National Health Service (NHS). Funding is predominately received from local and regional social care provision, although a large percentage of the residents are requiring nursing/health care**
- **Beds are often allocated and funded from a mixture of sources (public health or social care or from the resident)**
- **There are around 19,000 independently owned care homes in the UK**

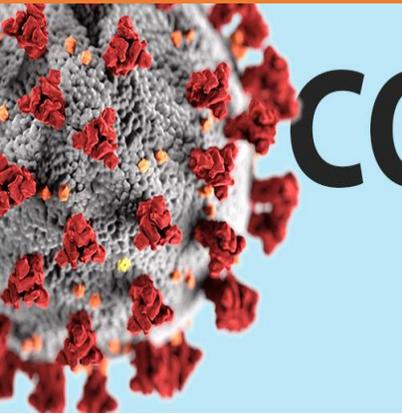
Covid-19 Global response and UK Government response

The World Health Organisation (WHO) declared that the outbreak of COVID-19 constituted a Public Health Emergency of International Concern (PHEIC) on **30th January 2020** (ECDC 2020). It was classed as a pandemic on the **11 March 2020**.

On the **23rd March 2020** the UK population was advised,
to stay at home, protect our NHS and save lives

*Prior to this on the **17th March 2020**, NHS England and NHS improvement wrote to all health Trusts to advise to “expand critical care capacity to the maximum” (NHS England)*

A global response



COVID-19

CORONAVIRUS PANDEMIC



UK picture and rate of deaths reported

- **Current UK picture 285,416 cases reported, 44,220 deaths (as at 5/07/20)**
- **19,394 care home residents died in England and Wales (2/3 – 12/6) (ONS)**
- **Estimates suggest that 1-5 care home residents are infected in England (Newscientist)**
- **Of all deaths in England and Wales involving COVID-19 (registered up to 19/06/20) 63.5% occurred in hospital with the remainder mainly occurring in care homes (29.7%), private homes (4.6%) and hospices (1.4%).**

The theory is all well and good but remember why it is important



Study design

- This is a UK wide qualitative empirical study focusing on family carers who pre COVID regularly visited their relative
- Data collection has involved interviews (up to 5 planned per participant) over the period of post lockdown and into 'normal' visiting
- A topic guide was used to elicit responses from participants
- To date we have recruited 15 family carers and conducted 9 initial interviews

[Study details](#)



Timescales, where we are:

- Study conceived in March 2020 at DMU
- Expedited ethics received April 2020 and study launched
- Qualitative study using interviews (up to 5 per participant) and a rapid review
- To date 15 family carers recruited – looking for 25 – 30 to be involved
- Ongoing analysis and data collection as situation evolves

[Study details can be found here: https://www.dmu.ac.uk/research/centres-institutes/ihhpsc/project-information.aspx](https://www.dmu.ac.uk/research/centres-institutes/ihhpsc/project-information.aspx)

Preliminary themes

- 1. Pre-Covid 19 – How visits were constructed**
- 2. During lockdown**
 - Use of technology**
 - Variances across the sector**
 - Worries about the virus and increased ‘distance’ (linked to End of life (EOL) considerations)**

Pre-COVID - How visits were constructed



- Lengthy and regular
- Engaged in different social activities
- Sustained over a period of time
- Mental stimulation



During lockdown - use of technology



Variances across the sector



Care home has required time to prepare for relative visits



Relatives providing the technology



Some restricted visits indoors and outdoors



Worries about the virus and increased 'distance' (linked to End of life (EOL) considerations)

Coronavirus outbreak

Covid-19: risk of death in UK care homes 13 times higher than in Germany

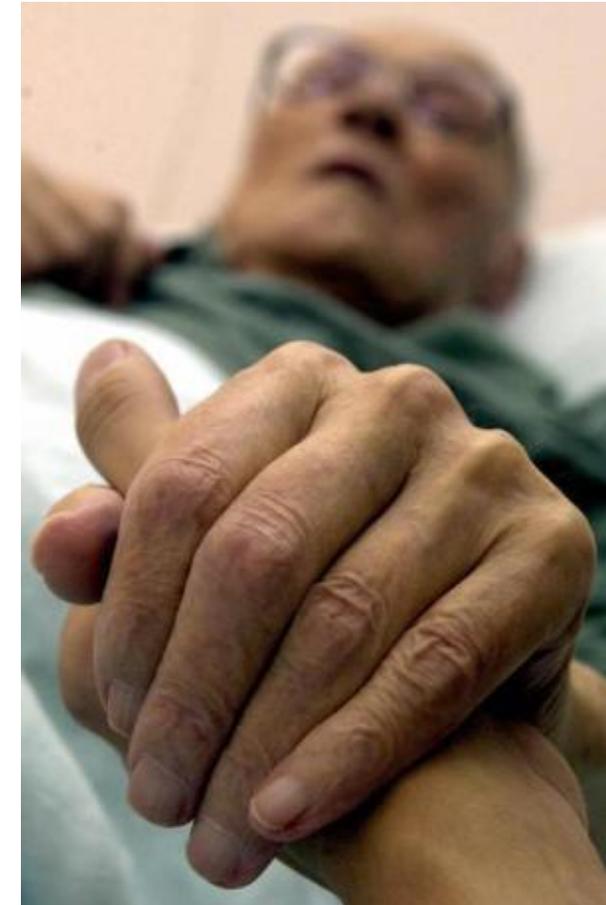
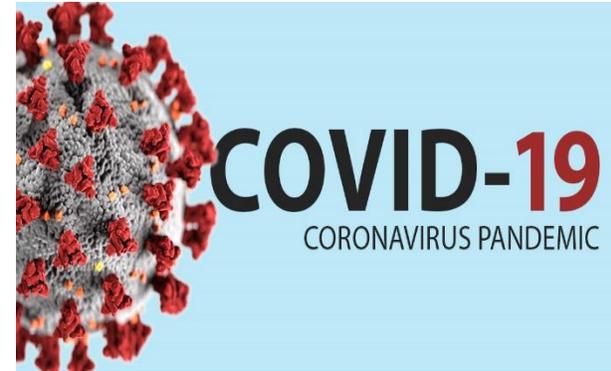
Exclusive: figures show Britain second only to Spain among major European countries

- [**Coronavirus - latest updates**](#)
- [**See all our coronavirus coverage**](#)



Worries about the virus and increased 'distance' (linked to End of life (EOL) considerations)

- **Increased levels of anxiety**
- **Feeling powerless/sense of loss**
- **Sense of responsibility – similar to those experienced when initially considering a care home**
- **Concerns that they may not get to see their relative again**



Limitations

- This evaluation was only based on the collection of qualitative data (interviews), it has not linked to other evaluations conducted (nationally or internationally)
- Timescales and resources



What can we learn in relation to the pandemic and care homes?

- This needs a partnership approach between care homes, residents and relatives
- We can prepare for future restricted access of any duration
- Now study connected to collaboration with Hull University and a national survey <https://hull.onlinesurveys.ac.uk/caring-from-a-distance-care-home-survey>
- Develop good practice guidelines based on the evidence from this study and working with care homes
- Review the current CQC guidance on visiting care homes
- Compare the picture for relatives here in the UK with other nations – what can we all learn?



Thank you

Thank you on behalf of the research team



Kathryn, Jayne Brown, Sarah Griffiths and Wendy Padley

Happy to take questions and discussion

 **#hinsliffk**