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Nurturing Innovation in Care Home Excellence in Leeds



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**

A report supported by



Remarkable
research for
healthy ageing

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SUMMARY

The COVID-19 pandemic is having a significant impact on the social care sector, in particular, people living and working in care homes for older people. The spread and outbreak of the virus in care homes has varied greatly across the sector, sometimes with devastating impact. The full picture of incidence and death rate from COVID-19 in UK care homes is not known, as the situation is still evolving. However, until effective vaccines for the virus are available, older care home residents will remain vulnerable and at greater risk of poorer outcomes if they contract COVID-19. Capturing lessons learnt about the symptoms, progression, and management of this viral infection in the older population (aged over 65 years) in England and sharing these lessons learnt with care homes that have not yet experienced an outbreak of the virus is crucial. This is the focus for our work with care homes in England.

This research was driven by the reflective and responsible leadership within the care sector. The National Care Forum (NCF) were very keen to learn as quickly as possible from the early days of the pandemic and to share this learning to support the sector. The work presented in this report therefore represents an important partnership between researchers at the University of Leeds and the National Care Forum (NCF), working with care home colleagues, to generate findings with practical relevance. We have conducted two phases of work (June to September 2020):

1. Interviews with frontline care home and NHS staff in June and July (n=35) to gather in-depth understanding of:

- the clinical presentation and illness trajectory of COVID-19 in older people (to date);
- what worked well, or what more was needed, for care and treatment; and
- lessons learnt for supporting infected older people to recover or die well.

2. Consultation with senior operational and quality managers in care homes in September (n=11) to establish:

- the resonance and relevance of Phase 1 findings; and
- strategies for managing COVID-19 at an organisational level within the home for the mutual benefit of residents, relatives and staff.

The findings are presented under the following themes:

1. Clinical presentation: COVID-19 does not always present as a cough and fever in older people
2. Unpredictable illness trajectory
3. Managing symptoms and providing supportive care: No 'magic bullet'
4. Recovery and rehabilitation: Promoting physical, cognitive and emotional well-being post-virus
5. End of life care: Being prepared and supported
6. Infection prevention and control: ensuring relevance, preventing complacency and promoting confidence among care home staff and residents
7. Promoting partnership through cross sector working and support

We have summarised the main lessons learnt by staff who participated in the study, followed by suggested strategies for care home managers and staff based on the experiences and reflections of study participants and, importantly, taking into consideration the care home context, acknowledging the needs (often complex) of people living, and also working, in care homes. We have presented the lessons learnt and strategies in boxes after each theme to provide accessible summaries for our care home colleagues. It is important to highlight that the findings are located within a particular time frame and context. It is recognised (and acknowledged) that over time understanding and knowledge about the presentation, trajectory, treatment and support of older people with COVID-19 is developing, alongside evidence and guidance. However, this practical knowledge collected during the first wave has real value for the care home sector, as we move into a second wave.

The willingness of colleagues to share their time while under considerable pressure of the first wave demonstrates strong and responsible leadership in the sector. Importantly, by learning and sharing the sector demonstrated a commitment to move from 'surviving' the first wave to finding ways to better manage (or 'thrive') in subsequent waves. These findings, however, also highlight systemic issues associated with underfunding, limited integration across health and social care and a lack of wider recognition and value of the contribution of the care home sector and (importantly) its staff. This crisis should prompt government and society to address these long-standing issues.

The report concludes with a call to action. Many of these actions can be grasped by the sector; however, there are levers and actions needed that are beyond the control of the sector and need support and action from government. Finally, a call for researchers and funders to work in partnership with the sector to ensure research fully addresses the priorities of residents, their relatives, staff, and care provider organisations. The COVID-19 pandemic has highlighted the need for research with and for the care home sector.

Our intention is for the report to remain an 'active' document with opportunities to continue learning lessons and sharing strategies for the benefit of those living and working in care homes. We will disseminate this report (version 1; 7 October 2020) widely and invite care providers to comment on resonance, relevance, and any gaps via an online survey (<https://leeds.onlinesurveys.ac.uk/less-covid-report-feedback>). The University of Leeds will lead on updating the report (by January 2021). Finally, we plan to co-create resources from this work that are useful for the sector. This will be led by NCF, working with the University of Leeds and care providers.

INTRODUCTION

Internationally, the total number of COVID-19 deaths in care homes are reported as between 19-72% (Comas-Herrera et al., 2020a). While the full picture of incidence and death rate from COVID-19 in UK care homes is not yet known, it is clear that COVID-19 is having a significant impact on the sector and the people who live in care homes (Department of Health and Social Care, 2020a; Scottish Government, 2020; Welsh Parliament Health and Social Care Committee, 2020; WHO, 2020). The initial Government focus on the NHS meant that not enough attention was paid to care homes at the start of the pandemic (Gordon et al., 2020). This left care homes feeling vulnerable and at more risk of an outbreak due to the vulnerable nature of the resident population, people living with dementia not always able to adhere to guidance, patients from hospital being transferred without a COVID test result, the environment not always being suitable for isolation practices, workforce challenges created by some staff needing to stay at home and isolate, increased use of agency staff visiting more than one home, withdrawal of face to face support from NHS services, and difficulties accessing appropriate personal protective equipment. Care homes are now considered to be at significant risk of COVID-19. Until effective vaccines are developed, older care home residents will remain vulnerable and at greater risk of poorer outcomes if they were to contract COVID-19.

There are currently approximately 420,000 residents living in UK care homes (Competition and Markets Authority, 2017). This vulnerable population - often living with frailty, multiple long-term conditions, and disability (Gordon et al, 2014) - are at far greater risk from COVID-19. The pandemic created a number of challenges in screening, diagnosis, management, and ongoing clinical and workforce challenges that created novel and unanticipated uncertainties for those caring for older care home residents (Spilsbury et al, 2020). Care homes are not part of the National Health Service (NHS): they are independent organisations, including for-profit chains, not-for-profit third sector organisations, and privately owned homes or companies with only a small number of homes (Competition and Markets Authority, 2017). Care is funded through a mix of self-funding, means-tested support from local authorities, and continuous healthcare funding from the NHS.

Care homes in England are comprised of homes with nursing, without nursing, or both (dual registered). There is considerable overlap in dependency levels and care needs amongst residents in care homes with and without nursing (Lievesley et al., 2011). However, there are important differences in the make-up of the workforce providing this care in the different types of care homes. In homes with nursing care, registered nurses are employed around the clock to supervise care delivery which is mainly provided by a large workforce of non-registered care staff. In care homes without nursing, the workforce is comprised solely of social care staff and the NHS provides input on an as required basis. Registered NHS nurses may also be involved in supporting any specialist care for residents in both types of care homes (e.g. palliative care). Care staff in either of these settings are employed at different levels and have different levels of preparation for their roles.

The independent and fragmented nature of the care home sector means that they are not always understood by the public. Prior to the pandemic, most media coverage of care homes was negative and demonstrated a lack of understanding for their complexity. For instance, there has been long-standing neglect of the care home workforce: no national accreditation for care home staff, limited opportunities for structured career progression, poorly paid staff and frequent reference to an unskilled work (Devi et al, 2020). This is important context for this research.

COVID-19 frequently presents atypically in care home residents (British Geriatrics Society, 2020). There is also concern about transmission of the virus by residents and staff who are pre-symptomatic or asymptomatic (Comas-Herrera et al., 2020b). The trajectory of the illness is not known, because this is a novel virus. During the period since this work commenced (June 2020), guidance related to the treatment, management, and care of patients with COVID-19 has been developed but it has not always been specific enough for the challenges being faced, or informed by, the care home sector (Lintern, 2020; Mitchell, 2020). Staff caring for older people (aged over 65 years) in care homes and the NHS (acute, primary/community) are continuously learning by experience about the virus. Systematically capturing this learning from those working at the frontline in care homes who have managed an outbreak (such as care home manager or registered nurse) or the NHS (for example, geriatricians) will generate important knowledge and understanding about the presentation and trajectory of the virus for the care home sector. For example, insights about symptoms, tipping points, how best to manage the virus at individual and organisational levels. Providing this learning in accessible formats for care homes who have not yet experienced COVID-19 is an important priority and particularly as the sector face subsequent waves of the virus. This is the focus of this work.

AIM AND OBJECTIVES

The overall aim was 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.

We addressed this overall aim through the following objectives:

1. To understand the clinical presentation and illness trajectories of COVID-19 for older people (aged over 65 years) being cared for in hospital and care homes;
2. To describe what worked well and what more is needed for care and treatment of older people with COVID-19;
3. To identify key lessons for supporting infected older people to recover well or, if that is not possible, to die well;
4. To share findings and lessons learnt (objectives 1 to 3) with care home senior staff to explore useful strategies for managing the infection at an individual and organisational level within the home for the mutual benefit of residents, relatives and staff; and
5. To explore the resonance and relevance of lessons learnt (objectives 1 to 4) with care home providers and to identify any gaps.

Further, and beyond the funded work, we will:

6. Co-create, with the care home sector, a range of resources to share the overall lessons learnt with frontline staff and provider organisations.

RESEARCH APPROACH AND METHODS

We used an appreciative approach (Sharp et al. 2016), working across disciplinary boundaries and care settings, to identify lessons learnt during the early stages of caring for older people with COVID-19. The work has been led by the researchers at the University of Leeds working in partnership with the National Care Forum.

The university research team have a large portfolio of work with care homes, including a university partnership with care organisations – Nurturing Innovation in Care Home Excellence in Leeds (NICHE-Leeds¹) (Spilsbury et al. 2018), and which replicates the Dutch Living Lab on Ageing and Long-Term Care (Verbeek et al, 2020). The aim of NICHE-Leeds is to undertake research to address questions that matter most to those living and working in care homes and that will promote quality of life, quality of care and quality of work. The university team were therefore well positioned to undertake this work due to:

- understanding of the care home context
- valuing and respecting those working in the sector and
- experience of working in partnership to address need and to co-create work with the sector to promote relevance, engagement and implementation.

The National Care Forum (NCF)² represents not for profit providers of care and support services across the UK to improve social care provision and enhance the quality of life, choice, control and well-being of people who use care services. At the beginning of the COVID-19 crisis in care homes, NCF had been supporting their members to share their experiences. This study was designed to capture lessons being learnt by staff caring for older people with COVID-19 and to consider useful strategies for managing the infection at an individual and organisational level within the home for the mutual benefit of residents, relatives and staff.

There were two phases to our work to address our objectives (1 to 5), using appropriate methods, during a 4-month period (June to September 2020):

Phase 1: Interviews with frontline staff (objectives 1 to 3) in June and July to gather in-depth understanding of:

- the clinical presentation and illness trajectory of COVID-19 in this population;
- what had worked well, or what more was needed, for care and treatment; and
- lessons learnt for supporting infected older people to recover or die well.

Phase 2: Consultations with senior operational and quality managers in care homes (objectives 4-5) in September to establish:

- the resonance, relevance, and any gaps in relation to Phase 1 findings; and
- strategies for managing COVID-19 at an organisational level within the home for the mutual benefit of residents, relatives and staff.

Objective 5 will be ongoing: we will disseminate this report widely and invite care providers to comment on resonance, relevance and gaps via an online survey (<https://leeds.onlinesurveys.ac.uk/less-covid-report-feedback>). This will help to maintain the report as 'active' with opportunities to continue learning lessons and sharing strategies for the benefit of those living and working in care homes. The University of Leeds will lead on updating the report. The final objective - to co-create resources - extends beyond this funded work. It will be led by NCF, working with the University of Leeds and care providers.

¹ <https://niche.leeds.ac.uk/>

² <https://www.nationalcareforum.org.uk/>

Data collection

All data were collected remotely by telephone or video conference (Microsoft Teams) due to restricted access to care homes and NHS settings by external visitors. Data were collected by researchers with experience of research with care homes and the NHS (KS, RD, AD, KH and AG). The researchers took written notes of the key issues and areas of learning raised by participants in Phases 1 and 2. With participants' permission, the interviews and consultation event were audio recorded. We did not transcribe the interviews but used these to add detail to the written notes (immediately post-interview) and to capture the words of participants.

Phase 1 interviews (conducted June to July 2020) were semi-structured (Appendix 1), which allowed scope for participants to share experiences that they considered important and relevant to learning about the care and management of COVID-19 in this population. The interviews lasted between 30 and 90 minutes. These findings were used to inform our discussions in Phase 2 of the work with senior operational and/or quality managers employed by care homes. Phase 1 findings were shared with Phase 2 participants in advance of the consultation event (hosted 3 September 2020). We focused on exploring the resonance, relevance, and any gaps in the findings with these senior staff, as well as, strategies for managing COVID-19 at an organisational level. The consultation event lasted 90 minutes. In advance of the consultation we asked participants to provide information about their role and their organisation (Appendix 2).

Participants

For Phase 1, we purposively recruited frontline care home or NHS staff, working in England, who had provided treatment and care for older people (over 65 years) infected with COVID-19. We invited these staff to participate in an exploratory qualitative interview. Participants were recruited through the team's professional networks, promotion of the study via relevant professional mailing lists (e.g. Royal College Nursing, British Geriatric Society, National Care Forum) and snowball sampling (where recruited participants suggested other potential participants). Staff who expressed an interest in participating were provided with study information (Appendix 3) prior to gaining consent (Appendix 4).

In Phase 1, a total of 35 frontline staff participated (June to July 2020): 18 participants were employed by care homes and 17 by the NHS, in either acute hospital (n=13) or primary/community (n=4) settings. Participants were recruited to represent a range of geographical locations across England. Care home participants worked in a diverse range of care homes, representing range of ownership, type, and size. Most participants were female (n=27) and of White British ethnicity (n=30). There was a wide age range (26-64 years), coupled with range of years of experience in health and/or social care (1 to 30 years). Table 1 provides detail of participant characteristics for care home and NHS (acute and primary/community) settings.

For Phase 2 we purposively sampled care home senior operational and/or quality managers and to represent care home type (with and without nursing), ownership, and size. We invited Phase 2 participants to a consultation event (3 September 2020). Participants were recruited through the National Care Forum and through Phase 1 participants explicitly nominating a senior colleague. Potential participants were provided with study information (Appendix 5) prior to gaining consent (Appendix 6). A total of 15 people expressed an interest in Phase 2. On the day of the consultation, 11 participants were able to attend (3 did not attend due to competing care and management responsibilities on the day and 1 due to personal circumstances). Table 2 provides further detail of 8 participants in Phase 2 (data were missing for 3 participants).

Table 1: Participant characteristics (Phase 1) (n=35)

	Care home staff (n=18)	Community staff (n=4)	Hospital staff (n=13)
Age range	38-62 years	41-52 years	26-64 years
Gender	Female n=16 Male n=2	Female n=2 Male n=2	Female n=9 Male n=4
Ethnic group	White n=16 Black n=1 Multiple ethnic group n=1	White n=4	White n=10 Asian n=3
Role	Director (of care or quality) n=5 Registered manager n=11 Registered nurse n=2	GP=2 Consultant nurse/ specialist nurse (frailty/ older people) n=2	Associate Director of Nursing n=1 Physiotherapist n=2 Occupational therapist n=1 Consultant Geriatrician n=6 Mental health nurse n=1 Palliative care nurse n=1 Operating Department Practitioner (ICU) n=1
Time in current role	<1 year n=6 >1 to <5 years n=6 >6 and <10 years n=1 >11 and <20years n=3 >21 years n=2	< 1 year n=1 >1 to <5 years n=1 >6 and <10 years n=1 >11 and <20years n=1 > 21 years = 0	< 1 year = 0 >1 to <5 years n=7 >6 and <10 years n=2 >11 and <20years n=2 >21 years n=2
Length of time working in health and social care	>1 and < 5 years = 0 >6 and <10 years = 0 >11 and <20years n=4 >21 and <30 years n=5 >30 years n= 9	>1 and < 5 years = 0 >6 and <10 years = 0 >11 and <20 years n=2 >21 and <30 years n= 1 >30 years n= 1	>1 and <5 years n=2 >6 and <10 years n=1 >11 and <20 years n=6 > 21 and <30 years n=1 >30 years n=3
Geographical location	East Midlands n=2 West Midlands n=3 North West n=1 London n=1 Yorkshire and Humber n=4 Oxfordshire n=1 South n=2 South East n=2 South West n=2	South n=1 West Midlands n=1 North East n=1 North West n=1	Yorkshire and Humber n=6 East Midlands n=3 North West n=1 South East n=1 London n=2
Type of home	Residential n=2 Nursing n=10 Dual registered n=6	N/A	N/A
Size	30 to 50 beds n=4 >51 to <80 beds n=7 >81 to <100 beds n=3 >100 beds n=4	N/A	N/A
Ownership	Private n=13 Charity n=5	N/A	N/A
Area of work	N/A	Frailty support team n=1 Community n=3	Medical ward (including elderly medicine) n=11 Cancer support/palliative care services n=1 ICU n=1

Table 2: Participant and organisation characteristics (Phase 2) (n=8)*

Participant characteristics	
Gender	Female n=11 Male n= 0
Ethnic group*	White n=6 Asian n=1 Multiple ethnic group n=1
Role*	Senior operational manager/ director n=3 Senior quality manager/ director n=2 Both operational and quality manager/director n=3
Duration employed in role*	>3 years to <5 years n=1 >5 years to <10 years n=2 10 years or more n=5
Duration employed in social care*	>5 years to <10 years n= 1 10 years or more n=7
Organisation characteristics	
Geographical location*	Participants worked for care home organisations located across 9 regions of England (North West, North East, Yorkshire and Humber, West Midlands, East Midlands, Greater London, South West, South East, East of England). Of these organisations: - 5 care homes located in 1 region only - 3 had care homes located in more than 1 region
Number of care homes in organisations*	Ranged from 1 to 328
Total bed capacity across organisations*	Ranged from 54 to 19,818
Types of care homes within organisations*	Residential n=1 Nursing n=4 Dual registered n=3
Organisation ownership type*	For-profit n=3 Not-for-profit n= 4 Charity n=1

*Information about role and organisation were not provided by 3 participants

Data analysis

Data were analysed using the Framework Method (Ritchie and Lewis, 2003) to identify main themes and lessons learnt. Comparing and contrasting data was important for our analyses so that we could understand similarities and differences between the experiences of participants by professional group, type of setting (care home and NHS) and type of care home (with or without nursing, size and ownership). The Framework Method supported this comparative approach. Steps of the Framework Method were followed: familiarisation with the data; coding and developing an analytical framework; applying the analytical framework; charting the data; and interpreting the data. We used a Microsoft Excel spreadsheet to chart our data. Our approach to coding was both deductive - focusing on symptoms, trajectory, treatment, and support - and inductive where we used open coding of lessons learnt. Data analysis was an iterative process undertaken by the research team (RD, KH, AG and AD), supervised by the Lead Investigator (KS). We have used the consolidated criteria for reporting qualitative studies (COREQ) checklist for reporting this study (Tong et al, 2007). We have used the words of participants when reporting our themes.

Ethical approval

The study was approved by the School of Healthcare Research Ethics Committee (REC reference: SHREC 19-026).

FINDINGS

The findings are presented under the following themes:

- Clinical presentation: COVID-19 does not always present as a cough and fever in older people
- Unpredictable illness trajectory
- Managing symptoms and providing supportive care: No 'magic bullet'
- Recovery and rehabilitation: Promoting physical, cognitive and emotional well-being post-virus
- End of life care: Being prepared and supported
- Infection prevention and control: ensuring relevance, preventing complacency and promoting confidence among care home staff and residents
- Promoting partnership through cross sector working and support

At the end of each theme we have summarised the main lessons learnt by staff who participated in the study, followed by suggested strategies for care home managers and staff based on this learning. Anonymised quotes are used to illustrate these themes.

To recap, **Phase 1** comprised interviews with 35 frontline staff working in care homes (n=18) and NHS (acute and primary/ community) settings (n=17). All staff who participated in the interviews (during June and July 2020) had provided care for older people with COVID-19. These interviews explored:

- clinical presentation of COVID-19 in the older population;
- illness trajectory; and
- treatment and support for older people to recover or die well.

Phase 2 comprised validation of these findings with a wider range of care homes. Findings were shared with senior operational and/or quality managers in care homes (n=11) who participated in an online consultation event (conducted on 3rd September 2020) to check for resonance, relevance and any gaps:

1. RESONANCE: whether the findings fitted with their experience in care home(s);
2. RELEVANCE: the usefulness of the findings for other care homes; and
3. GAPS: issues that are missing from the report that should be included.

Overall, Phase 2 participants confirmed Phase 1 findings and considered the findings worth sharing with other care homes, especially those who had not yet experienced COVID-19. They also added to the richness of the data by commenting on some of the related operational and quality management issues.

Clinical presentation: COVID-19 does not always present as a cough and fever in older people

In the early stages of the COVID-19 pandemic (March 2020), the Government guidance emphasised symptoms of COVID-19 as a new continuous cough and fever. Later (mid-May 2020), a loss or change in sense of smell and/or taste were added to this guidance list as key indicators of the virus. This is important context for our findings:

“We have to differentiate between what we saw in the early pandemic when we didn’t know so much about it and what we’ve seen later on. For the first few weeks during March and early April we thought we were looking for largely a respiratory virus and we were looking out for people with coughs, breathlessness and fever. As the pandemic has gone on we are realising that there a variety of COVID-19 symptoms and not just the original triad.” (Phase 1: Hospital Geriatrician 2)

Participants, who cared for older people in care home and NHS (hospital and community) settings, perceived the symptoms and clinical presentation of COVID-19 in this population as more varied and wide ranging than those listed in the Government guidance³. Some older people presented with ‘typical’ symptoms of cough, fever and loss of taste or smell (which sometimes manifested as a loss of appetite). However, both care home and NHS staff who participated in the study told us that the patterns in presentation of these symptoms in the older population varied. For example, a cough was not always present, and when it was it was not always persistent. Some older people presented with a high temperature in early stages but for others a fever was experienced with sudden onset at a later stage and often (in this situation) the fever would resolve as suddenly as it appeared. Sometimes the fever was more persistent at the later stages. A range of other symptoms were described as significant indicators of COVID-19 to observe for in this population (Figure 1). Care home staff, in particular, described that they noticed subtle changes in the appearance or behaviours of residents that helped them recognise they were unwell or “not quite themselves”; although in early stages, the link with COVID-19 was not always made by staff.

During the Phase 2 consultation, participants also observed that there were similar patterns in symptoms amongst those living in the same care home or within the same community or area of the care home. For example, in one care home a group of residents all experienced diarrhoea symptoms.

³ <https://www.gov.uk/coronavirus>

Figure 1: Symptoms of COVID-19 in the older population (in addition to listed Government guidance)

Gastrointestinal:	Diarrhoea Vomiting Reduced appetite Weight loss	Physical:	Reduced mobility Increased falls Fatigue 'taking to their bed' Tremors Seizures
Cognitive:	Increased confusion Delirium (due to acute illness)	Other:	Looking/ feeling 'unwell' Pallor Bleeding (from nose and eyes)

The key message from study participants was for staff and families to be alert and aware of changes in the health and well-being of an older person and to be concerned about a change, even if subtle. The presenting symptoms of COVID-19 in older people did not always comply with indicators highlighted in Government guidance. For this reason, it was suggested that staff should be alert to the possibility of COVID-19 and take actions to manage a 'suspected case' until ruled out:

"In the early days there were people with persistent coughs, there were people whose dementia accelerated very quickly and uncharacteristically, there were people who were generally unwell, lost their appetite, lost their mobility, and were just not presenting as they would normally present. It was incredibly varied. We were literally looking for all soft signs and testing for anybody that was showing symptoms of anything really." (Phase 1: Care Home Manager 2)

"Treating anybody who seems out of the ordinary as having it, and that's what we have done, because this could be it. So almost catastrophizing, but for the right reason." (Phase 1: Care Home Director of Care and Service Development 7)

Participants emphasised there should be systematic monitoring of all care home residents to detect subtle changes and/or deterioration. This monitoring included systemic observations, such as measuring blood pressure, pulse, temperature and respiratory rate, as well as measuring oxygen saturations. Phase 2 participants suggested that these observations should be carried out twice daily during the early stages of an outbreak (including suspected and confirmed) and then reduced as appropriate and as the situation changes in the care home to once daily. In addition, Phase 2 participants highlighted the importance of measuring the baseline health status of residents so that care home staff can monitor and more easily determine any changes in residents:

"I would suggest another piece of advice is to ensure staff know what the baseline temperature and observations are for residents as we found a lot of residents became unwell with a low grade temperature which was usually higher than their baseline temperature." (Phase 2: Care Home Chief Operating Officer 4)

Some care home staff reported using the RESTORE2 tool (Wessex Academic Health Science Network, 2020) to recognise physical deterioration and take appropriate actions, including escalation of concerns to primary and acute care professionals. The British Geriatric Society have included RESTORE2 in their COVID-19 guidance (British Geriatrics Society, 2020).

During the data collection period (June/July 2020), there was a growing awareness (due to testing) that some care home residents with COVID-19 were asymptomatic. This created particular challenges for managing the spread of infection and is considered further below in the 'Infection prevention and control' section.

The Government guidance created challenges for the care home sector, particularly in the earlier phases, due to rigid application of symptoms for accessing testing. The wide-ranging symptoms and subtle changes in an individual that were being recognised by frontline staff were not accepted as 'legitimate' indicators of COVID-19 infection. This significantly impacted on access to regular testing for older people residing in care homes, as well as older people in hospital awaiting transfer to a care home. Without testing, care home staff were working 'blind': not knowing which residents might be infected. The ongoing difficulties for care homes to access regular testing were highlighted by Phase 2 participants, alongside concerns about the time taken for results to be returned, test results going 'missing', and questions about the accuracy of results. Senior operational staff (Phase 2) emphasised the importance of frequent testing alongside the monitoring activities going on in care homes:

"At the point of admission a tool for baseline assessments. We were always playing catch up. This is an opportunity to now be proactive in particular with the frequency of testing... Testing is hit and miss - not as promised. There is such a delay with obtaining the results." (Phase 2: Care Home Chief Nursing Officer 5)

The care, treatment, and management of older people with COVID-19 is dependent on prompt diagnosis. Frontline staff have learnt important lessons about clinical presentation and symptoms of COVID-19 that can support the sector (Box 1). Phase 2 participants were keen to emphasise the importance of care homes planning and preparing for winter infections (including influenza, other respiratory and gastrointestinal infections) and further outbreaks of COVID-19, as well as addressing any ongoing health issue for residents prior to the winter period.

Box 1: Clinical presentation

Lessons learnt:

1. COVID-19 does not always present as a new continuous cough and fever in older people.
2. A range of symptoms have been identified in older people with COVID-19.
3. Staff (and families) should be alert to subtle changes in the older person and seek to 'rule out' COVID-19.

What can care home managers and staff do based on these lessons learnt?

- Educate all care home staff about the varied symptoms of COVID-19 in the older population.
- Ensure a system is in place for routine assessment and monitoring of care home residents so that staff are alert to changes (which may be subtle) in a person's condition (e.g. the RESTORE2 tool).
- Develop an understanding of the baseline status of residents (a resident passport) to enable care home staff to more easily recognise changes in a resident.
- Consider what is needed (training and resources) to develop staff skills and competence in systemic observations, such as measuring blood pressure, pulse, temperature and respiratory rate and provide clear guidance about who staff should report to any changes in a resident's condition.
- Manage a person as a 'suspected case' when changes are noted in their condition and until a COVID-19 diagnosis is ruled out.
- Access where available, and advocate for, regular and accurate testing, with timely results for residents and staff.
- Ensure confirmation of COVID-19 status for any person being newly admitted to the care home and isolate for 14 days, even if negative.
- Maintain close communication with GPs and other relevant healthcare professionals to ensure timely access to treatment care and support to meet residents' needs.
- Carry out winter planning and preparations to help residents stay well, working with other health care professionals to review and address any potential health issues for a resident.
- Communicate with colleagues in the sector to learn from their experiences of COVID-19 (e.g. in online forums, such as WhatsApp groups or Facebook groups, and other local groups and associations).

An unpredictable illness trajectory

Frontline care home and NHS staff described the illness trajectory of COVID-19 among the older people that they had cared for and suggested some potential patterns in the progression of the illness based on this experience:

- (i) about one-third who presented as unwell, who if admitted to hospital were discharged within 24 to 48 hours, and would quickly show signs of recovery; or
- (ii) of the two-thirds who were severely ill, often requiring oxygen and fluid therapy (see next section), about half were described as going on to die very quickly (within hours or days) and half were described as having a slow recovery, drawn-out over several weeks, with intermittent “ups and downs” in their recovery trajectory.

Overwhelmingly staff expressed the unpredictability of COVID-19 in terms of its trajectory and outcome for the group of people (two-thirds) who presented as severely ill, as summarised below.

Sudden deterioration

Participants (care home and NHS) described how quickly (in their experience) older people could suddenly deteriorate: they described cases where the older person was not ill and then within 2-3 hours became severely ill and died. Participants emphasised that this was not related to staff missing symptoms or signs of deterioration, systemic observations were often within normal limits:

“It was like they fell off a precipice within a couple of hours.” (Phase 1: Hospital Geriatrician 1)

When people died quickly, participants had learnt that this occurred in one of two ways: either the older person was struggling to breathe or they would suddenly collapse. Participants highlighted they were learning that COVID-19 was affecting blood clotting in some people and this put some older people at increased risk of a pulmonary embolus.

Late “dipping”

Of those older people who appeared to be recovering and were getting ready for discharge from hospital, there could be a rapid deterioration at about day 8 to 10 (but atypical presentation means certainty about time frames was difficult). These patients presented initially with similar symptoms (described as above) but a feature in this late “dipping” group was breathlessness – this was universally noted by NHS participants, along with marked changes on a chest x-ray. This indicated acute respiratory distress syndrome, and often these people would then die. It was not possible to discern who might be in this late “dipping” group.

Post COVID-19 syndrome

Post COVID-19 syndrome (which is sometimes referred to as Long COVID) occurred in a proportion of older people who appeared to be recovering but then at about day 14 became generally unwell. The signs and symptoms of this included the older person falling (when they would not normally fall), decreased appetite, weight loss, and being susceptible to other secondary infections, such as urinary tract infection. In these cases people recovered, but could be struggling for several weeks. In Phase 2 we heard from senior care home staff that they had noticed cases where residents experienced serious respiratory infections about 4-8 weeks post COVID-19.

Many older people in this group were described as having hospital stays of longer than 21 days. This group required care and support for their physical, cognitive and emotional well-being (discussed further below). These older people were considered less likely to regain the level of health that they had experienced prior to being ill with COVID-19.

Frontline staff have learnt important lessons about the unpredictable illness trajectory of COVID-19 that can support the care home sector (Box 2).

Box 2: Unpredictable illness trajectory

Lessons learnt:

1. Some patterns, based on participants' experience, were noticed in the illness trajectory for older people with COVID-19:
 - About one-third of older people will show signs of recovery within 48 hours;
 - About two-thirds of older people described as severely ill;
 - It was not possible to determine who died or recovered in the severely ill group.
2. Death could be sudden (within a couple of hours) or occurred at about day 8 or 10 when someone who appeared to be recovering suddenly deteriorated.
3. Older people who were severely ill and went on to recover were described as having a slow recovery, drawn out over several weeks and susceptible to further respiratory infections.

What can care home managers and staff do based on these lessons learnt?

- Educate care home staff about the patterns in illness trajectory and support them to cope with the uncertainty and loss.
- Enable advance care planning discussions between care home and/or healthcare professional staff with residents, and where appropriate their relatives, so that individual preferences for treatment and care can be understood and followed if there is sudden deterioration.
- Take the time to explain the unpredictable trajectory of COVID-19 to family members so that they are aware that their relative may suddenly and/or rapidly deteriorate.
- Consider what is needed (training and resources) to develop staff skills and competence to monitor residents who are severely ill and to access additional treatment, care and support when required, taking into account the older person's preferences and wishes.
- Plan for recovery and rehabilitation of older people with post-COVID syndrome.

Managing symptoms and providing supportive care: no 'magic bullet'

In the absence of an effective 'treatment' regime, frontline staff (across care home and NHS settings) described what they had learnt about symptom management and ensuring supportive care for older people with COVID-19. The unpredictable illness trajectory (as described above), coupled with varied (and again unpredictable) individual responses to interventions aimed at alleviating symptoms, created uncertainties for staff of how best to manage and support older people with COVID-19. Staff described how they diagnosed, "treated" and then waited for the outcome of how an individual responded (or not) to interventions and care:

"What I am trying to say is, in this group, they may have died without intervention but I don't think there is any way of predicting who gets worse. It's a case of give everyone the same and then wait to see what happened." (Phase 1: Hospital Geriatrician 1)

We present below what staff have learnt about managing symptoms and providing supportive care. It is important to highlight that frontline staff emphasised the importance of providing care in the best interests of the older person. This required an understanding of the wishes of the person (an issue covered in the section on illness trajectory above and in end of life care below). During phase 2, care home senior staff emphasised the importance of proactive care to give people the best chance of recovering from COVID-19, making sure that there was a clear 'intent to treat' option within the wider health system. However, they also cautioned that proactive care should be balanced with treatment burden and respect for individual wishes. Participants highlighted the importance of cross sector working to ensure older people received appropriate interventions and care in a timely manner. For example, relationships between a care home and primary and community services enabled access to a wider range of medicines to manage symptoms (described in more detail in the section focused on promoting partnership through cross sector working and support).

An important consideration for providing supportive care is ensuring adequate staff for this purpose. Phase 2 participants (in particular) discussed the challenges of providing supportive care during times of increased resident need, while experiencing staff shortages:

"During the peak of the pandemic, in order to facilitate supportive care with... staff reduction, we stopped everything but care delivery and an acute care plan." (Phase 2: Care Home Head of Quality 1)

In some cases, non-care staff (such as administrative staff) joined the care team - "all hands-on deck" - to ensure care delivery. During these periods, Phase 2 participants emphasised that fundamental care became a priority and that other usual procedures (such as reviewing care documentation or auditing) were put on hold, or "went out of the window". Digital care planning systems, where they existed, were invaluable in supporting effective and timely record keeping during these highly pressured periods:

"We are so relieved to have digital care plans as we managed to keep some basic records." (Phase 2: Care Home Deputy Chief Executive 6)

"I agree. We have now prioritised implementing electronic care records." (Phase 2: Care Home Head of Care 7)

In addition, technology was used to remotely support residents (discussed further below under Reducing the impact of social isolation) and to reassure staff during an outbreak and when implementing changes to practice and procedures:

“The use of technology has been vital in maintaining communication for residents and employees. We also used this to undertake virtual tours in terms of quality audits to support managers they were doing the right things.” (Phase 2: Care Home Head of Care 7)

Managing symptoms

The range of interventions used by frontline staff (in both care home and NHS settings) for symptom management included:

- Pyrexia: individuals who presented with a high fever and/or headache were often prescribed paracetamol.
- Respiratory infection: antibiotics were often prescribed at an early stage for individuals presenting with symptoms of a respiratory infection because it was not possible to determine if the infection was bacterial or viral.
- Pain: small doses of lorazepam and/or oral morphine were prescribed (for some individuals) for pain relief. Frontline staff reported the variable effectiveness of these medicines for managing pain for older people.
- Dehydration: subcutaneous fluids were administered to some individuals who refused oral fluids (usually in the first 5 days) in NHS settings (and in some care homes) to maintain hydration. GPs and geriatricians expressed some concerns about the safe administration of subcutaneous fluids and cautioned that when used they should be administered slowly. Care home staff expressed some concerns about the skills and competence of staff to administer fluids subcutaneously. Frontline staff expressed concerns about the invasive nature of administering fluids through a cannula under the skin, and that some residents and staff were reluctant to use this as a treatment.
- Agitation: small doses of lorazepam were prescribed when individuals demonstrated signs of agitation and were generally perceived by frontline staff to offer benefits and alleviate signs of distress for these individuals.
- Hypoxia: oxygen was prescribed variably to treat hypoxia (including symptoms such as breathlessness, rapid breathing, pallor, confusion, cough, or wheezing). It was often used in the hospital setting. Care home staff reported that oxygen was not routinely used in this setting. GPs reviewed individual cases within the care homes to assess potential benefit of oxygen therapy. Frontline staff raised issues related to providing oxygen in the care home setting. These were the safe administration and storage of oxygen and the reliance on the GP to examine individuals and assess which residents might benefit from oxygen therapy. In care homes with nursing, the presence of registered nurses (employed by the home) mitigated some of these risks. It was considered more challenging in care homes without nursing because a registered nurse was not present 24-hours a day on site to support oxygen therapy.
- Breathlessness: oxycodone and oral morphine were prescribed to relieve breathlessness, and were generally perceived to by frontline staff to offer benefits for individuals

Frontline staff working in hospital settings (geriatricians, physiotherapists and occupational therapists) identified additional interventions for symptom management that were not described by community-based staff or care home staff. Nonetheless, understanding that these additional interventions can be available in hospital settings for older people who are severely ill is important information for care home staff. These interventions included:

- Proning: frontline staff reported that changing the body position of an individual to prone (chest and face down) helped to alleviate breathing difficulties for individuals with COVID-19. However, this should be used intermittently, and it was emphasised that the technique should be taught prior to use by staff in health and care home settings. Knowledge and skills for de-proning are equally important.
- Low dose anti-inflammatory steroids: Dexamethasone was prescribed for some individuals in hospital to reduce inflammation in the lungs, to boost appetite and to promote alertness. This was perceived by hospital frontline staff to have benefits for some individuals.⁴
- Artificial nutrition: prescribed for some individuals in hospital with no oral intake.

“If people have low oxygen saturation levels, get them onto their tummy. If they can’t tolerate that, support them onto their side.” (Phase 1: Hospital Physiotherapist 11)

Frontline staff also emphasised the importance of medicine review for individuals with COVID-19 as part of their management. For example, adjusting or pausing antidiuretic medicines may be appropriate for individuals with a reduced fluid intake and it may be appropriate to closely monitor blood sugars. Medicine reviews could be undertaken for care home residents with GPs, nurses and pharmacists. Phase 2 participants raised the crucial need to consider flu vaccinations for both residents and care home staff as part of their preparations for winter infections. It was reported that there can be variations in uptake of the flu vaccination by staff groups of different ages: younger staff (aged 18-25 years) are less likely to have the vaccination. These participants also highlighted challenges associated with the availability, purchasing, storage, and administration of these vaccines. In some areas, community pharmacists were supporting the sector by administering flu vaccinations (free of charge) at the care homes. Other participants highlighted a potential role for Registered Nurses employed in nursing homes to help administer flu vaccinations in residential homes in the area.

Providing supportive care

Frontline staff emphasised the importance of supportive care for older people with COVID-19, alongside symptom management. This included: maintaining nutrition and hydration; reducing the impact of social isolation; and maintaining levels of activity.

Maintaining nutrition and hydration

As described above (see clinical presentation section) older people with COVID-19 were often reluctant to eat and drink. Frontline staff attributed this loss of appetite to the effects of the illness (including extreme fatigue), and also due to a reduced sense of taste and smell. It was often difficult for staff to determine the cause, particularly for older people with dementia who were not always able to explain how they were feeling or what they may be having difficulties with. In hospital, when an individual had been intubated, then this could also have an impact on eating patterns and affect swallowing for these individuals.

4. Dexamethasone was tested in hospitalised patients with COVID-19 in a national clinical trial (RECOVERY) and was found to have benefits for critically ill patients (National Institute for Health and Care Excellence, 2020)

Frontline staff across both NHS (hospital and community) and care home settings described the importance of ensuring regular nutrition and hydration:

"You need to be persistent, persistently trying and not giving up. Don't give up if they say they don't want to eat. They may not be able to communicate that. You, you just have to keep on trying." (Phase 1: Hospital Geriatrician 10).

To promote this vital area of supportive care, staff emphasised the importance of:

- monitoring of dietary intake;
- encouraging older people to eat and drink;
- offering regular smaller meals where appropriate that are high in calorific value, appetising, and easy to swallow (examples provided included soups, yoghurts, or liquidised strawberries and bananas);
- understanding individual food preferences (and contacting people who know the individual if they are unable to express these preferences); and
- including dieticians, as part of the multidisciplinary team, to support this area of care.

Reducing the impact of social isolation

Frontline staff (across settings) highlighted the importance of caring interactions with older people to promote well-being and to prevent the negative impact of social isolation. This was considered particularly important due to the emotional difficulties experienced as a result of restricted family visiting in both care home and hospital settings. Staff perceived that those older people who had some level of social interaction appeared to do better, and in contrast, those who were isolated deteriorated quickly, particularly those living with dementia. Care home staff (in particular) described the importance of maintaining hope for older people during the period of lockdown to maintain their well-being and prevent decline:

"Sometimes people decline because they have given up hope." (Phase 1: Care Home Director 7)

Care home staff described how they tried to address this and their approaches to promote social interaction for older care home residents. Care staff were encouraged to interact with residents during every day caring interactions (for example during mealtimes or when providing personal care) and also to create opportunities to engage residents with meaningful activities: family members were contacted (where possible) to discuss suitable ways of promoting this if staff were uncertain of what would be considered meaningful by a resident. Residents without a positive COVID test result were able to sit in communal lounge and dining room areas, while adhering with physical distancing guidelines. Staff shared that they developed more outdoor activities and entertainment, for example a singer in the car park, a garden tea party, and an outdoor exercise class. When residents tested positive for COVID, they were encouraged to isolate in their room for the period recommended in Government guidance. Care home staff and (where employed) activity coordinators provided in-room activities; for example, listening to music, completing jigsaws, reading books. Periods of isolation were difficult for residents and staff who emphasised the importance of residents being able to 'see' others. Staff contact in the room or residents being able to see people passing the door or through the window were considered helpful ways to reduce feelings of isolation.

The sudden withdrawal of family and friends from the care home environment affected not only residents, but also, family, friends and staff. Family were, understandably, described as anxious about the health and well-being of their relative. Frontline staff explored ways to maintain resident contact with their family members and friends. This included writing letters and post cards, video calls (although this could be difficult for someone with dementia), 'window visiting' or meeting in a garden at the home when physical distancing could be facilitated.

Phase 2 participants highlighted that as care homes had started to reopen, family visitors expressed concerns about the decline of their relative's physical health and cognitive function. This decline was difficult for family members to witness, process and accept. Participants reiterated the importance of family support and maintaining clear, regular, honest and open dialogue between the care home and families. Some care homes had used a weekly newsletter which included organisation level information (for example, the number of positive COVID-19 cases and actions being taken to manage the situation in the care home). The care homes also tried to convey personal information to keep families informed about their relative and any changes in their condition or state.

Maintaining levels of activity

Frontline staff across all settings recognised the rapid physical deterioration of older people with COVID-19: individuals experienced fatigue, lethargy, and reduced mobility. It was considered essential for care home and NHS staff to minimise the impact of decreased activity levels: potential de-conditioning of muscles and development of pressure ulcers. The challenge within a care home environment, where there were both residents with and without a diagnosis of COVID, was to ensure that collective activity was safe and minimised the spread of the infection. Some care homes were able to create zoned areas to be able to care for all residents with the virus in an area of the home that was separate to where those residents without the virus were cared for. However, the ability of a care home to be able to use this technique was dependent on the physical space and layout of the care home (this is addressed in the infection prevention control section). When possible, the residents were encouraged to walk in their care areas without concern for cross infection. However, this was particularly challenging when zoned areas were not possible and further complicated when residents with dementia walked with purpose outside of the room in which they were being isolated. Care home staff explained the delicate balance of managing this situation to maintain the safety of all residents while trying to minimise the impact on an individual resident, who may become agitated or distressed if they are not able to freely walk.

Frontline staff have learnt important lessons about managing symptoms of COVID-19 and providing supportive care that can support the care home sector (Box 3).

Box 3: Managing symptoms and providing supportive care

Lessons learnt:

1. During periods of increased resident need and staff shortages due to COVID-19, care home staff may need to focus on meeting the fundamental care needs of residents and document this in a core care plan.
2. Digital or electronic care planning systems are hugely helpful for staff to maintain care records during an outbreak.
3. In the absence of a treatment regime, there are interventions that may be useful for managing the symptoms of COVID-19 for individuals.
4. Context will determine the appropriateness of the delivery of these interventions and will be dependent on the skills and competence of staff.
5. Supportive care should be provided alongside interventions to manage symptoms to promote physical, psychological, and emotional well-being.
6. Where family or friends are integral for the care of the older resident, care home staff should seek ways to maintain engagement.
7. Family and friends may require support when visiting after a period of lockdown as they may notice considerable changes in their relative or friend (such as physical deterioration or cognitive decline).

What can care home managers and staff do based on these lessons learnt?

- Create and use core care plans during an outbreak of COVID-19 in the care home to document the provision of fundamental care to residents when there is overall increased resident need and staff shortages.
- Explore the use of digital or electronic care planning systems to replace paper-based documentation in the care home.
- Consider possibilities for introducing a new role in the care home to offer emotional support for residents and to support families, while care staff focus on fundamental care.
- Ensure advance care planning discussions have occurred with residents and family members to determine treatment and care preferences.
- Foster positive relationships between colleagues in the wider health and social care system to ensure the health and well-being needs of the older person are met and facilitate access to appropriate expertise and services.
- Monitor individual responses to treatments and offer supportive care.
- Determine opportunities and resources for developing the skills, knowledge and competence of care home staff to better meet the physical, psychological, and emotional needs of older people.
- Develop mechanisms to support frontline staff to ensure their well-being and to help them manage uncertainties related to the care and management of older people with COVID-19.
- Emphasise the importance of supportive care, alongside the management of symptoms, to maintain nutrition and hydration, reduce social isolation and maintain physical activity (where possible).
- Determine individual preferences of residents (for example food likes and dislikes and meaningful activities) and engage family members or friends, if necessary, to determine these preferences.
- Ensure ongoing support for family and friends who are not able to visit during lockdown restrictions and develop ways to maintain open, clear and regular communication to keep them informed about what is happening in the care home, as well as, update on any personal changes in the condition or state of their relative or friend
- Work with care home chefs to develop meal plans that meet individual preferences and meet dietary needs (for example foods easier to swallow).
- Consider the care home environment and whether it is possible to create zoned areas (for residents with positive test results) that decrease social isolation and encourage activity within the zoned area.
- Aim for comprehensive administration of flu vaccinations for all staff and residents and explore opportunities for support from others (e.g. community pharmacists or GPs and/or registered nurses from other care home or NHS settings).

Recovery and rehabilitation: promoting physical, cognitive and emotional well-being post virus

Care home and NHS participants highlighted that many older people would need a period of recovery and rehabilitation due to the significant longer-term impact of COVID-19 on their physical, as well as cognitive and emotional, health and well-being. Phase 2 participants emphasised the need to also consider the recovery and rehabilitation needs of residents who had not contracted COVID-19 but had experienced prolonged periods of reduced activities and social isolation, which will have impacted on their quality of life. There were concerns among senior care home staff that as society recovered from the first wave of the outbreak and lockdown eased (e.g. opening of schools, universities, restaurants, and leisure facilities) that there would be decreased focus on care homes. They highlighted the importance of a shared plan for recovery and rehabilitation.

Staff had learnt that the post-virus recovery for individuals was unpredictable and varied. Providing rehabilitation for older people was, therefore, perceived as essential. Concerns were raised about the limited access to therapy and rehabilitation services for care home residents pre-pandemic. This needed to be addressed urgently to meet increased demand, following COVID-19. While acknowledging this required extra resources, participants across care home and NHS settings considered it essential for the older population to be offered ongoing support for recovery post virus and suggested this required urgent consideration by commissioners. During the Phase 2 consultation, participants described the Hospital Discharge Service operating model and Government funding, via the NHS, to help cover the cost of post-discharge recovery and support services, rehabilitation and reablement care for up to six weeks following discharge from hospital (HM Government, 2020).

Based on their experiences of providing supportive care to older people following an acute phase of illness, participants across care home and NHS settings described what they considered necessary to provide the longer-term support and rehabilitation for older people recovering from COVID-19. This needed to be provided at an individual level, but also required a system level change to support care home organisations to be able to deliver this ambition for therapy and rehabilitation services. Participants raised the following as areas that they considered should be incorporated into the post-virus recovery phase care for older people (at the individual level), both those recovering from the virus and those who had experienced social isolation and decreased activities during the outbreak in care homes:

- **Opportunities for improving exercise tolerance:** While rest was recognised as important in the acute phase of illness, participants emphasised the importance of reintroducing exercise for older people to minimise “deconditioning” that results from inactivity. There were concerns that spending months at reduced levels of activity (due to the virus or due to lockdown) impacted on physical health and fitness of older people, including their strength, stamina, suppleness, and skill. Therefore, introducing opportunities for exercise, alongside goal setting and pacing, was considered an important part of the recovery phase for many older people:

“Pacing people and understanding their individual needs, doing a bit everyday exercise wise and going at their pace is important.” (Phase 1: Hospital Physiotherapist 11)

“I agree about increasing well-being now and getting more exercise to address muscle wastage as a result of being indoors for so long.” (Phase 2: Care Home Deputy Chief Executive 6)

- **Creative approaches to engage older people with exercise:** The challenges associated with supporting older people to exercise were recognised by participants, particularly for older people with cognitive impairment or dementia. Strategies to make exercise interesting and/or relevant were advocated by participants. For example, clear and simple instructions, or showing by example, such as throw and catch with easy-to-catch items such as small bean bags to help with strength and co-ordination development.
- **Enhancing sense of broader well-being:** Participants recognised the impact of social isolation and loneliness on older people as a result of COVID-19, particularly as a result of being quarantined. They described decreased cognitive and emotional wellbeing for many older people post-virus and suggested that exercise could offer support and minimise this impact. Phase 2 participants emphasised the need to 'thrive and not just survive'; highlighting older peoples' well-being and emotional needs, alongside their physical needs. Maintaining residents' relationships outside of the care home (i.e. with family members and friends) was considered essential to address feelings of isolation and low morale. When visits in person were not possible this should be facilitated by using technology. Giving older people information, encouragement, support, and motivation to maintain, or indeed increase, their level of exercise was advocated by participants. Ensuring that people moved about (even in their room when in isolation), rather than "taking to their bed", was considered an important component of recovery and rehabilitation. Finding ways to address cognitive and emotional well-being was considered as important as physical rehabilitation.
- **Instilling a sense of hope for individuals:** Care home staff, in particular, noted the importance of providing care that promoted a sense of individual hope and positivity. This was perceived as key for older people and their recovery and to prevent them "giving up". Activities that promoted rehabilitation were considered crucial for this purpose. Participants recognised that engaging physiotherapists, occupational therapists, and activity coordinators during the recovery phase supported the older person and also encouraged other staff to adopt a rehabilitative and positive approach in day-to-day care.

There was recognition among care home and NHS participants that there needed to be system-wide planning by commissioners and policy makers to ensure the right level of support for older people recovering from COVID-19.

Rehabilitation for older people post-virus, many who would already be living with co-morbidities, will take time. The impact of COVID-19 was recognised as devastating and debilitating for many older people, i.e. those who experienced severe symptoms and were "bed bound" for an extended period. Participants had learnt that physical deterioration (or "deconditioning") meant that many of these individuals experienced decreased levels of physical function and were slow to recover. Longer-term therapy and rehabilitation services, including specialist pulmonary rehabilitation, were considered crucial for this purpose. This will require increased professional input and time, and increased commissioning and funding of such care and services, particularly in care home environments. Participants indicated that involving intermediate rehabilitation teams in recovery care planning was essential and a resource that all older people should be able to access to promote equity in health and care provision. However, Phase 2 participants expressed concerns for external health care professionals visiting care homes, without testing and highlighted on-going problems with the testing, track and trace systems.

Frontline staff have learnt important lessons about recovery and rehabilitation post-virus that can support the care home sector (Box 4).

Box 4: Recovery and rehabilitation

Lessons learnt:

1. COVID-19 will have a significant impact on the physical, as well as cognitive and emotional health and well-being of many older people.
2. Recovery and rehabilitation should be provided for all residents to address periods of reduced activity and social isolation during extended periods of lockdown.
3. Recovery for older people post-virus is unpredictable, varies by individual, and often takes time.
4. Planning for therapy and rehabilitation services for older people is an important aspect of the recovery phase.
5. There is limited (and variable) access to therapy and rehabilitation services for older people, and particularly for care home residents, which creates challenges for care home and NHS staff when supporting older people to recover.

What can care home managers and staff do based on these lessons learnt?

- Foster positive relationships between colleagues in the wider health and social care system to promote rehabilitation for older people during the recovery phase and to ensure access to appropriate expertise and services for this purpose.
- Engage in discussion with commissioners about the rehabilitation needs of older people to support better recovery and outcomes and the provision and funding of therapists and services to meet this need.
- Access Government funded post-discharge recovery and support services, rehabilitation and reablement care for up to six weeks following discharge from hospital.
- Educate care home staff about the importance of recovery and rehabilitation to promote physical, cognitive and emotional well-being of older people post-virus.
- If possible, employ exercise instructors who can train care staff or alternatively encourage staff to access online resources for exercise programmes for older people.
- Consider purchasing portable equipment, such as Motitech bikes (<https://motitech.co.uk>).
- Promote opportunities for older people to increase their levels of exercise post-virus through creative approaches, as well as goal setting and pacing, to enhance levels of physical activity and to minimise “deconditioning”.
- Provide older people with information, encouragement, support, and motivation to maintain, or indeed increase, their levels of exercise for physical, cognitive and emotional health and well-being.
- Encourage older people to exercise in own room when quarantined.
- Determine opportunities and resources to support care home staff to adopt a positive rehabilitative approach to care.

End of life care: being prepared and supported

Participants described the unpredictable trajectory of COVID-19 for older people and that a proportion of older people died (sometimes very quickly) with the virus. Staff emphasised the importance of providing treatment and care which was consistent with the older person's preferences and to avoid inappropriate treatment burden when the person was nearing the end of life (EOL). Care home and NHS participants shared the important lessons they had learnt and the need to be prepared to promote a comfortable, dignified and respectful death for an individual. They also highlighted the importance of support for frontline staff due to the impact on their personal well-being that caring for older people during the pandemic had on them.

Understanding individual preferences

Participants emphasised the importance of providing the opportunity for advance care planning so that an individual (with family members when appropriate) can plan their future care and support, including medical treatment, whilst they have the mental capacity to do so. Participants recognised the ongoing importance of these discussions but were keen to emphasise that COVID-19, with its unpredictable trajectory, had thrown the importance of these discussions into sharp focus. Participants described that there should (where possible) be documentation in a care plan which is accessible and available to all relevant care home and NHS frontline staff (including, for example, the GP and paramedic staff):

- whether or not the older person would want to go to hospital and receive active treatment;
- their preferred place of death; and
- details of any specific individual, cultural and spiritual requirements at end of life.

Participants (frontline care home and NHS staff) recognised the challenges of these discussions and suggested different tools which could be used to facilitate discussions and to complete advance care plans or, at a minimum, discuss treatment and specific preferences at the end of life with individuals. Phase 2 participants highlighted the importance of considering these wishes during pandemic circumstances and advocated for the development of brief prompts or an 'essentials' toolkit to support staff to have these conversations when under pressure (see for examples, Figure 2). Finding ways to gather this information efficiently during a pressured situation was thought to be essential.

Figure 2: Tools to support advance care plan discussions with individuals (and family members when appropriate)

- RESPECT - Recommended Summary Plan for Emergency Care and Treatment (<https://www.resus.org.uk/respect/respect-healthcare-professionals>)
- DNACPR - (Do Not Attempt Cardiopulmonary Resuscitation) (<https://www.resus.org.uk/library/additional-guidance/guidance-dnacpr-and-cpr-decisions>)

Ensuring comfort at the end of life

Participants shared their experiences of caring for older people with COVID-19 at the EOL; and advocated use of medicines to manage symptoms, including pain (for example, morphine and midazolam). Issues around access to and the timely administration of medicines were discussed, particularly by care home frontline staff.

Care home staff described that, where possible, they had in place anticipatory medicines (prescribed by a GP) for residents, where this was considered appropriate by staff, residents and, when relevant, family members. When these medicines were not in place then this created difficulties of access to, and timely administration of, medicines to manage and control symptoms at EOL. Participants described increased pressure placed on the medicines supply chain during the peak of the COVID-19 pandemic. When medicines were unavailable, then this caused distress for the older person and the staff caring for them. In the early stages of the pandemic, staff were not able to re-purpose medicines or to request a supply of medicines for storage in the care home (in case required). This caused frustration and upset for care home staff. However, it is worth noting that later guidance (issued 23 April 2020) permitted this when the resident for whom it was originally prescribed no longer needed it (Department of Health and Social Care, 2020b).

Frontline staff working in, or with, care homes without nursing (also known as residential homes) described situations where an older person with COVID-19 deteriorated at a rapid rate (covered in the illness trajectory section). Delays in access to a health care professional (for example a community nurse, or a palliative care specialist) often delayed the timely administration of EOL medicines. Some participants reported delays of up to 6 hours. A geriatrician advocated in this situation for the prescription of lorazepam: this could be administered by care staff, either orally or sublingually (placed under tongue) if the older person was not able to safely swallow medicines.

Restricted family visits at end of life

Participants (care home and NHS staff) described that family visiting to care homes and hospitals was restricted to minimise the risk of COVID-19 transmission. At the end of life, this was a difficult, and often distressing, situation for all parties. Participants suggested this lack of connection at the end of life impacted on the bereavement process for relatives. A hospital geriatrician summarised this:

“Family being present for a death is important for three reasons. First, relatives can be relatives and staff can be staff. Second, it is important for the grieving process for relatives, if they are not there this creates a “complex bereavement”. And third for contextualization; they need to see the extent of deterioration, so they understand why their relative has died.”
(Phase 1: Hospital Geriatrician 1)

In the absence of family members, and to prevent older people dying alone, participants (care home and NHS) described cases where frontline staff had provided older people with emotional comfort and support at the EOL. Participants emphasised this important aspect of care and suggested staff valued ‘being there’ for people at the end of their life. It was also important for families to hear from a health and social care professional that: “I was there”.

Staff working in care homes described the dedicated approaches put in place to enable family members to visit their relatives at the EOL in a way that was safe and reduced risk of potential spread and transmission of COVID-19 within the care home. The following measures were described: restricting the number of relatives and the duration of their visit; explaining the risks (asking relatives to sign a disclaimer); assessing temperature on arrival; asking relatives to wear

full PPE; asking relatives to self-isolate for 14 days after the visit; and using designated entrances and exits for relatives visiting the home (and to minimise relatives walking around the care home). Staff described that while these restrictions helped to facilitate visits in a controlled way for some relatives, it was not always possible for those relatives who were 'shielding' (with pre-existing health conditions) to visit in person. Other solutions were offered for these relatives:

"We did allow families in. We invited families to come and sit with them in the last few hours wearing full PPE, we checked temperatures, and went through disclaimers. Allowing family in was really important. Not all family could come in because they were shielding, and we did video calls with them. One lady spoke to every single member of her family before she died by video in the last few hours." (Phase 1: Care Home Manager 2)

While participants described the use of video calls and "window visits" to enable family members to spend time with their dying relative, concerns were raised by some participants with regard to the ethics of using video calls and whether the individual dying would have consented to wanting their relatives involved in this way when they were unconscious.

One care home manager spoke about a 'family liaison officer' role in the care home, where a member of staff was employed to support and communicate with relatives. The family liaison officer regularly communicated with relatives, providing updates about their relative's condition, and supporting families with their bereavement. Through keeping in regular touch with relatives the care home were able to involve relatives in decision-making during EOL care, and ensure any specific requests were also considered (for example spiritual/religious wishes).

Supporting the physical and emotional well-being of frontline staff

Participants (care home and NHS) described the "shocking and devastating impact" of COVID-19 on themselves and colleagues due to the pressure and intensity of work and the significant loss of life that they experienced in a short time period. This emphasised that frontline staff needed mechanisms for accessing support during the COVID-19 pandemic. This included their physical and emotional well-being, as well as providing necessary training and support with end of life care.

Whilst the emotional impact for all frontline staff was described, there was particular concern about the impact on care home staff because of the close relationships built between staff and residents, sometimes over years. Care home staff often described residents as "family members" and losing many residents in a short period was devastating for staff. In addition, this was coupled with guilt or a sense of personal failure because the person had died:

"Rather than focusing on 'stopping the virus' and 'rescuing' patients, staff should also be encouraged to consider what they can do and what care they can provide to ensure someone is comfortable, pain free and dies with dignity." (Phase 1: Hospital Lead Nurse for Palliative Care 5).

Phase 2 participants highlighted the importance of supporting staff to have time to grieve. During COVID-19 staff were not able to attend funerals or meet with relatives to offer comfort and support: something they would do under 'normal' circumstances. There was additional emotional strain on staff when they, in the absence of family members, were needed to provide comfort to older people at the EOL. Participants described cases that were traumatic for staff: in particular deaths where older people with COVID-19 were breathless or agitated. These experiences were particularly difficult for less experienced frontline staff.

Participants suggested that the emotional impact of the pandemic was likely to be long lasting, and therefore, long-term support for staff needed to be provided. Participants (care home and NHS) described approaches for this support: access to senior staff to debrief and seek support; dedicated staff bereavement and counselling support; good team working and team relationships; EOL care support groups; good leadership that values staff contributions and their vital role in EOL care; and taking time away from work to rest and personally recover and “heal”. These approaches were described to work well if frontline staff felt confident in seeking support. There were concerns raised that not all staff felt comfortable with this and so leaders and managers had a key role to help these staff recognise and access appropriate (and helpful) support.

Offering training in EOL care was also recognised by participants as essential to prepare frontline staff and promote their confidence in this important aspect of care. Frontline staff in care homes received support with training from local palliative care teams and local hospice staff. While EOL training generally aimed to prepare staff to look after someone who was dying, there were other specific aspects of training that were considered important. This included checking staff working in care homes were comfortable with EOL care plans, having difficult conversations and breaking bad news to families, verifying deaths, and correcting misconceptions around EOL medicines (such as administering morphine does not kill people). Staff specialised in palliative care emphasised that frontline staff need to be trained in a way that helps staff consider what is a ‘good death’, and see that as a positive (rather than negative) caring experience and a worthwhile endeavour during the pandemic.

Supporting the organisation

There have been high numbers of deaths of older people in care homes with COVID-19.

Participants described some of the additional organisational support offered to care homes for EOL care during the pandemic. There was concern for care homes about the verification of deaths, particularly for residential homes (care homes where there is no registered nurse on site). A participant described local death verification services where a team of staff were employed to support residential homes to verify deaths. This service was perceived to have ensured deaths were confirmed in a timely way, and reduced the impact on the workload of frontline healthcare staff (such as GPs or district nurses) who would have previously been required to visit the care homes to verify deaths.

Changes were also made to the process around how statements of intent were issued (i.e. medical staff issuing notifications of expected deaths). GPs were able to issue these virtually (prior to the pandemic these had to be done in person), and statements of intent were completed to cover a 28-day period (previously statements covered a 14-day period). This helped care homes prevent situations where coroners were needed to investigate unexpected deaths, and also prevented family (and care staff) distress during bereavement.

Participants working in community settings (care homes and community hospitals) described delays with the removal of deceased residents by funeral directors and particularly during times when the care home was experiencing higher than usual numbers of deaths. This required sensitive management by the care home manager and staff and to ensure the necessary support was in place for staff and the families.

Frontline staff have learnt important lessons about end of life care during the pandemic that can support the care home sector (Box 5).

Box 5: End of life care

Lessons learnt:

1. Due to the unpredictable illness trajectory for an older person with COVID-19 it is important that individuals (with family members when appropriate) have the opportunity to discuss treatment and specific preferences for end of life care.
2. An older person with COVID-19 can deteriorate rapidly and so access to health care professionals and medicines is important to ensure they receive necessary care to manage symptoms and to promote comfort for the individual at the end of their life.
3. Peaks in the virus outbreak can create localised shortages of EOL medicines for care home residents.
4. Restricting family visits at the end of life is distressing for all – residents, their relatives and staff.
5. In the absence of family members, frontline staff have an important role in “being there” for an individual at the end of their life.
6. Effectively communicating with family members when their relative is dying, and particularly in circumstances when they cannot visit, is important for bereavement care and support of the family.
7. COVID-19 has had a devastating impact on frontline staff due to the pressure and intensity of work and the significant loss of life that they experienced in a short time period.
8. Care expertise is essential to support an older person dying with COVID-19 to have a dignified, calm and pain free death.

What can care home managers and staff do based on these lessons learnt?

- Promote timely opportunities for staff to engage in advance care planning discussions with older people (and where appropriate their family members).
- Consider how resident's wishes can be fulfilled during pandemic circumstances, in particular with regard to what is possible in the circumstances.
- Ensure individual preferences are clearly documented in a care plan that is accessible and available to all relevant care home and health care frontline staff.
- Consider requesting the prescription of anticipatory medicines for older people where appropriate to ensure access to and timely administration of EOL medicines to promote comfort for the individual.
- Standard operating procedures for the re-use of medicines support the repurposing of medicines in a care home that are no longer required by an individual but required by another resident and so can promote timely access to medicines.
- Promoting opportunities for family members to visit their relative should be assessed on an individual basis and facilitated by care home staff.
- Where face-to-face visiting is not possible then alternative strategies should be considered, but these should be mindful of the wishes of the older person who is dying.
- Consider opportunities for a dedicated family liaison officer or staff member who can support and communicate with family members and offer bereavement support.
- Determine how best to support frontline staff with their physical and emotional well-being and accept this should be long-term ongoing support due to the significant impact of COVID-19 on staff.
- Support leaders and managers to help care staff recognise and access appropriate (and helpful) support (e.g. individual/group sessions for staff, using support services where possible, for example Admiral Nurses).
- Communicate with care staff the importance of a ‘good death’ and that their contribution to end of life care is important and valued.
- Consider what is needed (training and resources) to develop staff skills, competence and confidence in end of life care.
- Determine local procedures for timely verifications of death in the care home during an outbreak.

Infection prevention and control: ensuring relevance, preventing complacency and promoting confidence among care home staff and residents

Participants (from both care homes and the NHS) described the importance of infection prevention and control (IPC) in care homes during the pandemic. This included strategies for minimising person-to-person contacts and cross infection, as well as effective use of personal protective equipment (PPE) and infection control policies. Phase 2 participants emphasised the impact of staff shortages and the challenges this presented fulfilling extended IPC measures and practices.

Minimising cross infection

Participants described 'cohorting' and 'zoning' approaches - many referring to the Bushproof method (Fewster, 2020) - to manage residents with suspected or confirmed COVID-19 in separate parts of the care home from those without the virus. It is important to point out that care home staff reported doing this in advance of any Government guidance and demonstrates their leadership, creativity and innovation at this difficult time. However, approaches for zoning residents dependent on their COVID status were only considered possible if the physical environment (care home layout and space) facilitated it and the staff resource was sufficient: some care home managers stated this was not possible in their environment or because of staff shortages. NHS participants highlighted solutions used in the NHS which may be applicable for the care home environment, for example Derby doors, inflatable doors to segregate areas.⁵

One example of how a 'COVID-19 zone' was created is presented. Residents who tested positive with the virus were moved into a lounge area, set up as a communal ward area. The lounge was large enough to place resident beds and manual handling equipment (e.g. hoist) while still maintaining distance between residents. Benefits were recognised through this communal set up: residents were not isolated in a single room and so were able to see other residents and staff; care workers were able to provide timely and efficient care for residents; and access to an outdoor space from the lounge area meant residents (and staff) had the freedom to walk outside with no risk to residents in the care home without the virus. It was acknowledged that this temporary move created confusion for some residents but the benefits for the majority were considered to outweigh this and staff supported residents during the process and their stay in an unfamiliar environment. It is not known how this may be perceived by relatives.

The cohorting of staff (where staff numbers permitted and regardless of the physical environment) was also important to minimise cross infection: staff exclusively cared for either COVID positive or negative residents, or where zoning was not possible care workers were isolated to specific floors/communities in the care home. This is now recognized in Government policy (Public Health England, 2020). Care home managers shared their experiences of isolating both care and cleaning staff to specific communities of residents to minimise cross infection. Care staff only mixed with staff in their cohorted area: they did not mix with staff in other parts of the care home. Other staff (e.g. catering or laundry) did not enter care environments nor come into contact with care staff: food and laundry were placed outside the entrance to the care community for collection by care staff. In addition, staff working in different cohorts were not permitted to share lunch times or breaks. Phase 2 participants emphasised that minimising cross community working was only possible with enough staff numbers and difficult (or impossible) when care homes were operating with significant staff shortages. The Adult Social Care Infection Control Fund (Department of Health and Social Care, 2020c) was introduced in May 2020 for this purpose: ***"to support adult social care providers, including those with whom the local authority does not have a contract, to reduce the rate of COVID-19 transmission in and between care homes and support wider workforce resilience"***.

5. <https://fabnhsstuff.net/fab-stuff/the-derby-door>

When planning for cohorting staff and/or zoning of residents in designated areas, participants also described the importance of considering the route by which staff and visitors entered and exited the care home, and where they 'don, doff and dispose' of PPE. This was to reduce the risk of COVID-19 being brought into the care home or being transferred between areas. A care home manager described creating a PPE 'donning, doffing and disposing' area, which was located at the care home entrance and exit areas. In this case the care home also avoided care workers wearing their own clothes by providing staff with scrubs which care workers changed into when entering the home and changed out of when exiting the home. Showering facilities for staff to use as they arrived and left the care home were also advocated. It was recognised among participants that for cohorting and/or zoning to be effective then they needed to be embedded in broader infection prevention and control practices and policies that all staff and visitors were aware of.

Consistent staffing of care homes was considered essential for infection prevention and control. It was recognised that the pandemic had created a range of staffing challenges for care homes but that these manifest in different ways. Staffing levels were affected by factors such as staff illness, shielding due to existing health conditions, resignations (for various reasons including existing health problems) and staff absences created by a fear of going to work and possibly infecting their own families. This situation added to the pressures of staff who continued to work with lower numbers of available staff and who often worked additional hours – working longer days or extra shifts – in an effort to maintain care delivery for residents. It also created a sense among remaining staff of being deserted by their colleagues during the crisis. Where staffing levels fell below 'safe' levels then agency staff were used but this introduced another element of risk for these homes: agency staff working in different homes created increased risks for cross infection across care homes. Knowing the recent history of placements for agency staff or securing exclusive and committed agency staff for the care home were important for minimising risks. This later became part of the Infection Control Fund Regulations.

Phase 2 participants were keen to highlight the impacts of COVID-19 on their considerations for recruitment and employment of staff. Recruitment now needs to assess attitudes towards COVID-19 among candidates, alongside gaining a sense of the candidate's perception about responsibility for care and working as part of a team. Changes were also being considered for employment contracts so that staff understood the requirement to wear specified PPE when providing direct care. These were significant learning points from the pandemic for senior operational and quality managers in care homes.

Minimising complacency

Care home participants described the unprecedented challenge that COVID-19 had created for supporting staff in infection prevention and control practices and procedures, and the use of appropriate personal protective equipment (PPE): including how to wear, remove and dispose of it. Training and clear guidance was paramount to ensure frontline staff worked in ways that contained and prevented the spread of COVID-19 across the care home environment.

Ensuring all care home staff were trained effectively was described as a challenge by care home participants due to: the non-specific guidance being issued by the Government (i.e. not care home focused); the often conflicting guidance; and the constant updating and reissuing of guidance. Care home participants described the importance of ongoing training and support for care home staff during the pandemic. They highlighted that the training offered by the NHS was often too basic and offered too late: training needs to build on what staff already know. Finding effective ways to communicate with staff working in different roles in the care home was considered crucial, alongside targeted and appropriate training and guidance for staff groups to promote relevance and prevent complacency.

Participants spoke about increasing vigilance with cleaning tasks and the importance of regularly disinfecting and cleaning to help prevent spread of COVID-19. Care home managers described recruiting more housekeeping and domestic staff to increase the frequency of cleaning and using cleaning rotas and checklists to record cleaning activities. Participants described increasing cleaning of specific high touch points, such as all wheel chair handles, bed rails and light switches. Domestic and housekeeping staff were provided with training focused on cleaning and IPC, for example, specifics around using disposable cloths and mops and not reusing materials in different areas of the care home to minimise spread of the virus.

Promoting confidence

Participants (care home and NHS) emphasised the importance of care home staff having access to appropriate PPE for their protection and to prevent virus transmission in the care homes. There were varied reports by care home participants related to the sourcing and accessibility of PPE during the early stages of the pandemic (March to April 2020): although all reported inflated costs of PPE due to demand and supply issues. Where it was difficult to source PPE and supplies were low then care home managers highlighted the stress and anxiety that this created for them. All participants highlighted the focus on the NHS for PPE supplies and relative neglect of care homes. Participants were keen to emphasise the importance of being prepared with adequate supplies of PPE for an outbreak of the virus in care homes, as well as the additional supplies for visitors to the care home. Many participants reported having learnt important lessons during the first wave of the pandemic about ensuring PPE supplies. PPE was critical for ensuring staff confidence at work.

During the early stages of the pandemic, care home participants reported that care staff were fearful and anxious about the protective equipment available to them when providing care for residents with COVID-19, particularly staff who had pre-existing conditions. Media images of the PPE being worn by staff in intensive care units, as well as the level of PPE being worn by paramedic staff that visited the care homes, created anxieties for care home staff that the PPE being used in their environment was not offering sufficient protection. Many care staff challenged the management teams about this issue and participants described strategies to manage this and to promote staff confidence in levels of PPE:

- the important role of the manager in supporting and reassuring staff;
- reassuring care staff that other community health care staff (for example GPs or community nurses) wear the same level of protection, reinforced if care staff witnessed healthcare professionals visiting the care home in same PPE;
- senior care staff, managers and senior staff wearing the same PPE; and
- directing care staff to national PPE guidance.

One care home manager emphasised the importance of language that reinforces support for care staff to access adequate PPE:

“Staff do not want to hear a manager saying you can’t wear whatever because I’m down to the last 50!” (Phase 1: Care Home Manager 9)

When testing was available for staff and they received negative results then this also promoted confidence for care staff in PPE. However, Phase 2 participants emphasised the ongoing challenges of accessing regular and accurate testing for care home staff. Participants described cases where test results had gone missing, delayed reporting and/or “unclear” results. This was experienced by all senior operational and quality managers in Phase 2:

"We tested 142 staff last Thursday, Results returned Tuesday this week all unclear. What a farce!" (Phase 2: Care Home Director 8)

During the Phase 1 interviews, the increased risk for the Black and Minority Ethnic (BAME) community was raised by a small number of participants. Two NHS participants described the death of their colleague from COVID-19 and that this was shocking and created fear among the BAME community. One participant described the risk assessment and management strategies that the hospital had put in place and felt some reassurance due to these measures. It was raised that many staff working in care homes come from BAME backgrounds and so this will require consideration beyond normal risk management procedures to protect these 'at risk' staff. This might include considering redeployment to a "less risky" environment, a job review, or shielding (if necessary). This was reinforced by Phase 2 participants and for the ongoing safe deployment and management of care home staff.

Encouraging staff to minimise risks when not at work was also discussed by participants. One GP raised the issue that staff from BAME backgrounds often live with a number of other people from their families and this can pose a greater risk for these individuals. Other participants raised the importance of safe transportation for staff: to avoid the use of public transport some care home providers had provided a dedicated taxi service for staff.

As well as promoting staff confidence, participants (care home and NHS) described the importance of promoting confidence for older people when accepting care from care staff wearing PPE. This was particularly important when caring for a person living with cognitive impairment or dementia. The following quote illustrated the confusion for a care home resident when staff wore PPE:

"He said, "Hey, boss come here, come here. When you going to get rid of these fing space men and give me my girls back?" If you had a spaceman coming towards you to carry out extremely personal care you would resist. And they did!"*** (Phase 1: Care Home Head of Care 4)

Participants highlighted the importance of clear communication with residents and using familiar language and non-verbal cues when providing care. Facemasks hide facial expressions and muffle sound: these are critical when engaging in care. Care home participants highlighted the importance of reminding staff to do all they can to promote familiarity and their relationships with residents. Phrases captured from care home participants about this issues included: "it's all about the staff approach"; "you can still see people's eyes and their body language"; "you smile with your eyes and residents see that"; "I still know you today as well as I did yesterday".

Frontline staff have learnt important lessons about infection prevention and control that can support the care home sector (Box 6).

Box 6: Infection prevention and control

Lessons learnt:

1. Deploying strategies to minimise person-to-person contacts is essential to control the spread of COVID-19.
2. If the physical environment permits, then 'zoning' residents and providing care only for residents with or without the virus in separate communities (areas of the home) may minimise cross infection.
3. If staffing numbers are adequate, then 'cohorting' care and cleaning staff to care only for residents with or without the virus may minimise cross infection.
4. Gather knowledge and understanding of where agency staff have been working and where possible secure exclusive and committed use of agency staff.
5. Clearly signed, designated routes for care staff and visitors to enter and leave the care home, as well as to put on and dispose of PPE, should be planned and well communicated.
6. Support should be offered to family members who may not be accustomed to donning and doffing PPE to maximise efficacy of PPE and reduce infection transmission.
7. Ensure staff change into their uniform when they enter the care home and remove it prior to leaving the premises and where possible shower before entering and leaving the care home.
8. Communicate the importance of risk management behaviours for staff during their non-working hours and offer (where possible) transportation for staff to get to work.
9. Catering and laundry staff should limit their direct contact with care communities and care and cleaning staff in these communities.
10. Staff from different communities within the home should not share lunch times or breaks.
11. Targeted and appropriate training and guidance on infection prevention and control for care home staff is essential, building on what is already known.
12. Protocols for enhanced cleaning of the care home and sufficient numbers of staff who understand these protocols is essential for reducing cross infection.
13. Planning for the sufficient supply of PPE is important.
14. The care home manager has a key role in reassuring care home staff and promoting their confidence in PPE and infection control and prevention procedures and practices.
15. Care home residents may not understand use of PPE and staff have an important role in maintaining relationships, by using familiar language and non-verbal cues, to promote residents' confidence and to support relatives when visiting a family member when wearing PPE.

What can care home managers and staff do based on these lessons learnt?

- Consider ways to minimise person-to-person contact and whether 'zoning' and 'cohorting' of residents and staff would be appropriate strategies to minimise cross infection in the care home environment.
- Explore solutions from other settings that may facilitate the zoning of areas in the care home, for example Derby doors.
- Determine need for, and possibilities to resource, extra cleaning and domestic staff to manage enhanced infection prevention and control procedures and to regularly clean 'high touch' surfaces.
- Consider how to minimise contacts (particularly at lunch and break times) between staff caring for communities with and without the virus.
- Plan routes for care staff and visitors to enter and leave the care homes and to put on and dispose of necessary PPE.
- Consider the provision of showering facilities for care home staff to use when entering and leaving the care home.
- Work with current PPE suppliers (and explore contingency measures with other suppliers) to ensure supplies continue to be reliably available and consider building up a stock of PPE for 3 months advance.
- Determine ways to reassure staff and promote confidence in the PPE provided to protect them and residents.
- Conduct appropriate health and risk assessments for all staff and consider the needs of those at particularly high risk, including Black and Minority Ethnic (BAME) staff and appropriate reassurance and review of roles.
- At interview, assess the attitudes of candidates towards COVID-19, and their sense of responsibility to care and team working.
- Consider making changes to employment contracts so staff understand the importance of wearing specified PPE when providing direct care, unless there are mitigating health reasons.
- Determine ways to promote confidence of older people when accepting care from care staff wearing PPE.
- Encourage staff to promote existing relationships with residents by using familiar language and on-verbal cues when providing care in PPE (particularly facemasks) and also make family members aware of the importance of this when wearing PPE during a visit to their relative.

Promoting partnership through cross sector working and support

Participants (care home and NHS) emphasised the importance of partnership working across sectors during the pandemic to ensure appropriate and timely responses to the needs of older people with suspected and diagnosed COVID-19.

Securing access to the right care and support for residents

Care home participants described the support they had accessed from primary and community healthcare professionals during the pandemic and how pivotal this had been for managing the needs of residents in their care. However, not all experiences were positive in the early stages: some care home participants perceived that there had been a withdrawal of support and services from primary and community services and that they “felt alone” (some said they were “abandoned”) to manage their resident population, some of whom experienced severe symptoms and deteriorated rapidly. In these circumstances, participants emphasised the need for support from, and communication with, GPs and primary and community healthcare professionals to meet the healthcare needs of residents. However, this was not the experience for all participants:

“I have very strong feelings, that the abdication of partnership working, where actual physical visits were required, was actually a Breach of the Public Sector Duty of Care. The withdrawal of services such as dietetics, SALT [speech and language therapists], DoLS [Deprivation of Liberty Safeguards], MHTs [Mental Health Teams] was wrong.” (Phase 2: Care Home Head of Quality 1)

Phase 2 participants described care homes employing Registered Nurses to step in for NHS employed District Nurses and provide care for older people living in supported living apartments or residential care. The withdrawal of NHS district nurses directly impacted on the work of care staff in residential homes:

“I think one issue was the DNs [District Nurses] tried to enforce some of their duties on our non-clinical staff with no consultation or discussion.” (Phase 2: Care Home Head of Care 7)

Some care home participants reported continued access and support from primary and community teams. However, this rapidly moved to ‘virtual’ or remote consultations as these healthcare teams tried to minimise visits to the care homes to reduce spread of the virus. Participants described communication through video calls and text messages (including out of hours support), as well as conducting virtual ward rounds and multidisciplinary team meetings (which could include care home staff, GPs, palliative care team, pharmacists, geriatricians, community nurses, hospice team) to provide comprehensive care for residents. When implemented, the rapid shift to virtual working was perceived as working well; however, this varied considerably across local areas. In some circumstances, primary care teams provided equipment to care homes to enable care home staff to record blood pressure and temperature readings to be used in the virtual ward rounds and inform decision-making. One GP described that while virtual support appeared to work reasonably well and helped to restrict external visitors in the care home, there were occasions where he conducted a ward round in person, wearing appropriate PPE. The GP described that these occasional face-to-face visits were well received by the care home and promoted positive relationships and mutual support during a time of crisis.

During phase 2, participants highlighted the significant time implications for care home staff of

these new ways of working. The impact of COVID-19 on how care home staff spend their time was felt in many areas, including virtual assessments and testing regimes:

"I do think that future working, as we live with COVID-19 should also include aspects of time management placed on the care homes. For example: a virtual DoLS assessment can take up to 3 hours of a manager's time; testing can take up to 24 hours per week of staff time. And this all pulls from other things." (Phase 2: Care Home Head of Care 7)

The continued partnership working across primary, community and care home staff supported the consideration and discussion of treatment and care decisions for residents, including appropriate transfer to hospital. Of course, during the pandemic, residents had other healthcare needs: not all decisions about care and treatment were COVID-19 related. However, participants (care home and NHS) highlighted the challenge of transferring an older person across care settings during the pandemic.

Care homes as much of a priority as the NHS

Participants (care home and NHS) acknowledged that in the early phases of the pandemic there was priority given to 'saving' the NHS and, as a result, hospitals were keen to discharge older people as soon as possible, including to care homes, to secure bed capacity and to manage the anticipated spike in COVID-19 cases. Phase 2 participants also described that some care homes were 'instructed' by NHS staff not to refer people aged over 70 years to hospital. The efforts made to 'save' the NHS left care homes feeling 'abandoned' and unsupported. Participants also acknowledged that discharging older people with COVID-19 (and those suspected as having the virus) contributed to the spread of the virus within care home settings. There was limited understanding in acute hospital settings at this time of the limited resources, equipment, support and guidance to manage the needs of older people with COVID-19 in care homes and to minimise its spread. However, Government policy was explicit that people needed to be discharged from hospital to free up NHS beds.

Some care homes accepted the admission of older people knowing they had COVID-19 and others, due to pressure, to accept the person without a test result. Participants in this situation described wanting to support the older person in an appropriate environment and to support the NHS. However, there was later anger at this situation; one care home manager described her anger and resentment of being used as "a COVID cleansing house" (Phase 1: Care Home Manager 1). Other care home providers (and managers) refused to accept people discharged from hospital with a positive COVID test result or without any test result. For many care home managers, they came under increased pressure from hospital staff and, in some situations the care provider company owners, but managers emphasised the need to resist this pressure and (sometimes) bullying behaviour to accept a referral:

"I don't have the staff you have. I don't have the PPE you have. I don't have the support services that you have. I don't have Covid in my home. So why would I accept a referral with a positive Covid test and introduce this to my home? No means no." (Phase 1: Care Home Manager 9)

"The focus was on the NHS, care homes were like the poor relations in the background." (Phase 1: Care Home Manager 13)

"I think we can all agree now that when people were sent to care homes in large numbers during March and April - although it seemed like a good idea at the time in that context clearly that did have a role in seeding infections in care homes." (Phase 1: Hospital Geriatrician 2)

Having learnt that admissions from hospital were a route for COVID-19 to enter the care home,

participants offered solutions for how this could be better managed for future waves of the virus. It was suggested by a range of participants that community hospitals could be converted to become a care equivalent of the NHS Nightingale Hospitals and older people could be cared for in these environments and quarantined for 14 days (at least) prior to moving to a care home. If these environments were not made available then discharges needed to be better organised, and older people discharged to care homes with the right level of post-acute support and care. One NHS participant described that discharges from hospital to care homes should be discussed and decided locally through collaboration and partnership:

“One thing that was really missing was locally agreed protocols and plans that are signed up to by all the relevant parties, about what is reasonable to do before we transfer someone to a care home; infection control nurses, directors of public health, infection specialists infection control nurses, all around a table with social care, care homes, acute, primary care and all agree the rules around who gets transferred. Acute hospitals were all really keen to clear the beds but didn’t understand that care homes couldn’t cope with the infection control.”
(Hospital Geriatrician 2)

Frontline staff have learnt important lessons about promoting partnership through cross sector working and support that can support the care home sector (Box 7).

Box 7: Promoting partnership through cross sector working and support

Lessons learnt:

1. Residents’ needs for treatment, care and support are better managed through cross sector partnership working, particularly between care homes and primary and community care and services and for appropriate transfer to hospital.
2. Virtual consultations worked well to meet residents’ needs and to minimise visits to the care home by external staff but there is inconsistent use of this technology across areas.
3. The discharge of older people with COVID-19 (and those suspected as having the virus) from hospital to care home was perceived to contribute to the spread of the virus within care home settings.

What can care home managers and staff do based on these lessons learnt?

- People working in NHS and care home settings need to understand each other’s contexts, value and respect each other’s work, and learn to work in better partnership with each other.
- Demand the support of primary and community care services and teams to meet the needs of residents.
- Request access to and embrace new ways of working with technology to promote timely and efficient access to treatment, care and support for care home residents from healthcare teams and services.
- Provide training for care staff to take on additional roles (where appropriate and resources are made available) to be able to better communicate a resident’s status and condition to primary and community health care professionals working remotely to make decisions about treatment, care and support.
- Work collaboratively across sectors to develop guidance for the safe discharge of older people with COVID-19 from hospital to care homes, including the potential for community hospitals (where available) to be utilised during the quarantine period.

LEARNING AND SHARING FROM THE FRONTLINE

This report presents lessons learnt from frontline care home and NHS staff who provided treatment and care for older people during the first wave of COVID-19 in England. Further, it offers suggestions about what care home managers and staff can consider during subsequent waves of COVID-19 outbreaks. These suggested strategies are based on the experiences and reflections of study participants (in both phases of our work) and, importantly, take into consideration the care home context, acknowledging the needs (often complex) of people living, and also working, in care homes. The knowledge created through reflection is important to share more widely across the sector. These lessons and suggested strategies will be of particular relevance for care homes that may not yet have experienced an outbreak of the virus. As we report (October 2020) there are concerns of the rise in numbers of infections (residents and staff) in UK care homes.⁶

The findings in this report represent the experiences of our participants of the clinical presentation of COVID-19 in the older population, the illness trajectory, and the treatment and support for older people to recover well and, in the sad event that recovery will not happen, to support a good death. The findings highlight important considerations during the pandemic for residents and their families, care home staff, and the staff who work with (but are not employed by) care homes, as well as the important role of wider systems of support for the sector. Key areas raised in the report relate to: diagnosis and testing; infection prevention and control; rehabilitative care to address periods of reduced activity and social isolation; advance care planning; partnership working between care home and NHS staff; electronic care plans; support for care home staff; developing new staff skill and competence (with necessary resources provided for this purpose); and mechanisms for shared learning across the sector.

These findings should be celebrated: frontline staff were willing to contribute their time to this work so that they could share and reflect on lessons learnt. This highlights the strong and responsible leadership in the sector. At a time when there was minimal, conflicting or irrelevant guidance for the sector, care home staff, organisations and bodies demonstrated responsiveness and maturity to promote and share learning during a crisis, with the sole purpose of benefiting the people living in care homes. Our findings represent a move by the sector from 'surviving' the first wave to finding ways to better manage (or 'thrive') in subsequent waves. These findings, however, also highlight systemic issues: endemic underfunding of the sector, limited integration between the health system and care sector, and a lack of wider recognition and value of the contribution of the sector and (importantly) care home staff.

The interviews with frontline staff were conducted during June-July 2020, and the findings were validated with care home senior operational and quality managers in September 2020. The findings presented are therefore located within a particular time frame and context. In the absence of guidance and limited evidence, this practical knowledge has value. However, it is recognised (and acknowledged) that over time understanding and knowledge about the presentation, trajectory, treatment and support of older people with COVID-19 is developing, alongside evidence and guidance. Hence, we present this report as a 'working' or 'active' document. It will be important to continue to consult with, and learn from, frontline care home staff, particularly as they develop their practice and evidence in relation to COVID-19, and to share this knowledge for the benefit of people living and working in care homes.

6. <https://www.nationalcareforum.org.uk/wp-content/uploads/2020/09/Stuart-Miller-letter-to-care-sector-11.09.20-PDF.pdf>

Finally, this work represents a partnership between researchers at the University of Leeds and the National Care Forum, working with study participants. The research team have a large portfolio of work with care homes, including a partnership with care organisations (NICHE-Leeds) to undertake research that will promote quality of life, quality of care and quality of work for people living or working in care homes (Spilsbury et al, 2018). The team therefore have a good understanding of the care home context, value and respect those working in the sector, and are used to working in ways that: (i) promote partnership to address need, (ii) co-create how best to do the work with the sector and discuss the implications of the findings with them, and (iii) make use of networks to share learning and resources that will help develop and support practice. This partnership approach enabled us to respond quickly to the concerns of NCF members and generate findings with practical relevance in an accessible format. The COVID-19 pandemic has highlighted the need for research with and for the care home sector. We consider this partnership approach should underpin all research with and for care homes to ensure it fully recognises the importance of practice and addresses the priorities of residents, their relatives, staff and care provider organisations.

CALL TO ACTION

The sector

- This research highlights the value of ongoing reflective learning and the importance of sharing collective expertise in care and in practice – **the care home sector must keep on learning and sharing, for the benefit of residents, relatives and staff.**
- It also highlights the importance of what care homes do to support the wellbeing and care of residents. **The sector has learnt a huge amount about how to provide good care in relation to COVID-19 and they must use this knowledge, so the people they care for can continue to thrive, as well as, survive.**
- The increased use of technology is also highlighted in these findings, both the value of digital planning systems and the use of technology to keep people connected and to enhance the care delivered by the care and health workforce. **The sector should continue to expand their use of digital technology to improve the way services are delivered.**
- This research shows how care staff stepped up to learn new skills rapidly but how this is not always valued or sufficiently recognised by the wider health and care system. **Where negative perceptions exist, then these should be challenged and there needs to be more formal recognition of the expertise of care home staff, within their various roles.**
- A resounding theme throughout this research is the importance of the care home workforce, highlighting their skill, dedication, resilience, and compassion. Nonetheless, the toll on staff over the last few months must be recognized. **There is an urgent need to support the wellbeing and mental health of the workforce to help them to prepare for the winter months ahead.**

The government

- Findings in this research show the direct impact of solely prioritising the NHS over the care sector in the early days of the pandemic. Social care must be seen as an equal partner, alongside the NHS. **Policy making, guidance, effective resourcing (including PPE), and plans for action must always be created in equal partnership with the care sector.**
- This research highlights the importance of the care home sector in caring for some of the most vulnerable citizens in society. **Urgent action is needed from the Government to invest in the care sector to enable better reward and recognition of the care workforce.**
- This research highlights the importance of effective, reliable and efficient testing of residents, staff and visitors for preventing and managing COVID-19. The Government now recognises the importance of regular routine testing across care settings and care services with the introduction of the whole-home testing programme. **However, more still needs to be done to achieve the implementation of regular routine testing for the whole of the care sector, including:**
 - Addressing the current delays to the processing of tests to ensure results are returned promptly.
 - Rapidly increasing the testing capacity for social care to cover all care settings, including day services.

- **Enabling testing for visitors to care settings, as well as Care Quality Commission (CQC) inspectors and visiting health professionals, and other people bringing services into homes, such as hairdressers and musicians.**
- This research highlights how the struggle to access reliable supplies of PPE at a time when the guidance was placing increasing emphasis on the need for extensive PPE compounded the pressures of the workforce. The Government has now committed in its Winter Plan to providing free PPE to the care sector. However, the timescales for ensuring that all care services receive the levels of PPE that they need remain unclear. **Urgent action is needed to ensure adequate PPE stocks across the care sector is an essential part of long-term planning to manage COVID-19.**
- This research highlights the importance of ensuring that older people who are recovering from COVID-19 have access to rehabilitation services. **Ensuring the appropriate range of specialist and timely care and support services for older people in care homes is essential and requires action by the Government to promote recovery and rehabilitation for care home residents.**
- This research highlights the importance of recognising that some of the early responses to the pandemic felt like a blanket approach to care homes and older people, be that in understanding symptoms, a clear intention to treat and provide clinical support, or the restrictions on visiting. **The Government needs to address this in future policy making and guidance and to ensure the individual needs of older people are at the heart of policymaking.**
- This research highlights the importance of systematically capturing early warning data from the care sector as the virus develops and manifests itself. **The Government needs to focus on efforts to improve coherent data collection and mechanisms for sharing and analysing these data to improve the COVID-19 response to ensure early warning signs are not missed again.**
- This research highlights the huge value that digital technology brings to the quality of care and to support the rapid identification and recording of key data about the trajectory of COVID-19. **Investment in digital technology is essential to support the sector to improve quality of care available through this technology and the connectivity it brings.**

Researchers and research funders

- This research provides insights about what has been learnt during the first wave of COVID-19. **Further and on-going research is needed to update this document in view of learning from subsequent waves.**
- This research focuses on the experiences of staff when providing care and support for residents and families during the pandemic. **Future work needs to explore the perceptions, experiences, and impact of COVID-19 for care home residents and their families and friends.** For example: intention to treat to alleviate symptoms and prolong life when desired by residents (and families); understanding end of life care during a life-threatening crisis; and supporting residents, families, and friends during future waves of the virus.
- This research describes perceived impacts of COVID-19 on the care home workforce, including: the emotional and psychological health of staff; increased role demands; areas for continuing personal and professional development; employment and deployment effects; relative differences in reward and recognition for staff; and impact for BAME staff. **More research is needed on how to effectively support staff and to alleviate these impacts.**

- This research highlights the impact of COVID-19 for care home providers. **Future research is needed to explore the operational and financial impacts of COVID-19 for the sustainability of care homes.**
- This research recognises the challenges for care homes to contain the virus in a collective living environment, particularly when it may be difficult for individuals to adhere to social distancing guidance due to cognitive impairment. **Research is needed on how new models of housing with care and support can address this issue.**
- This research demonstrates innovation during the crisis and the perceived positive impact of new technologies to enhance care and support for older people living with frailty and at the end of life. **Further research focused on the feasibility, acceptability and effectiveness of innovations and new technologies for residents, relatives and staff in care homes is required.**
- This research highlights the perception that care homes were abandoned at a time of crisis. It has also thrown into sharp relief issues that have long been known about, including lack of adequate funding, lack of integration across health systems and social care, and lack of understanding and value of the sector and its workforce. **Further research is needed to explore public, professional and policy perceptions of the role and responsibility of the wider health and social care system to support older people living with frailty in care homes and to address the whole system changes needed to meet the needs of our ageing population.**
- This research recognises the need for better partnership working with care homes to fully recognise the importance of practice and addresses the priorities of residents, their families and friends, staff, and care provider organisations. **This partnership approach needs to underpin all research with and for care homes to ensure it addresses what matters most for those living, visiting or working in care homes and using appropriate methods to address uncertainties and develop a robust and meaningful evidence base for the sector.**
- This research captures the tacit knowledge of expert practitioners working with older people (many living with cognitive impairments, including dementia), when scientific knowledge was limited and guidance did not always apply. **Research funders need to recognise the practical value of this form of knowledge for developing a sector relevant evidence base.**

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APPENDIX 1: PHASE 1 INTERVIEW SCHEDULE

LESS COVID-19 (PHASE 1): Version 1 (18-05-2020)
Ethics ID: HREC 19-026



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INTERVIEW SCHEDULE - PHASE 1 with frontline health and care staff

LESS COVID-19

Learning by Experience and Supporting the Care Home Sector during the COVID-19 pandemic: key lessons learnt so far by health and care practitioners working on the frontline

Questions about the participant:

Gender: _____

Job role: _____

How long have you worked in your current role: _____

How long have you worked as a health or care practitioner: _____

Questions about the organisation:

Do you work in a hospital organisation? Y/N, if yes, provide location details _____

Do you work in a care home? Y/N, if yes, please provide following details:

- Which region is the care home located _____
- Residential or nursing: _____
- Bed capacity: _____
- Type of ownership: _____

Question guide for interviews

How does COVID19 present (i.e. symptoms) in older people?

What is the progression of the virus in this population? Have you noticed any patterns in the illness trajectory? Are there any particular 'tipping points' that you think others should know about?

Are there any treatments that you have used that you think have worked well?

What do you think helps older people to get better?

What works well when providing care, and what more is needed?

What helps older people to recover well from COVID19, and what more is needed?

What is needed to help older people to die well, and what more is needed?

What are the main lessons you have learnt when caring for older people with COVID-19?

If you were to give colleagues any top tips for caring for older people with COVID-19, what would these be?

Are there any particular lessons you have learnt that you think need to be emphasised?

Is there anything else that you would like to add?

Thank you for taking part in this interview.

APPENDIX 2: PHASE 2 INFORMATION ABOUT PARTICIPANTS' ROLE AND THEIR ORGANISATION

LESS COVID-19 (PHASE 2): Version 3 (27-08-2020)
Ethics ID: HREC 19-026



UNIVERSITY OF LEEDS

CONSULTATION - PHASE 2 with care home senior operational or quality managers

LESS COVID-19

Learning by Experience and Supporting the Care Home Sector during the COVID-19 pandemic: key lessons learnt so far by health and care practitioners working on the frontline

PLEASE RETURN THIS FORM IN ADVANCE OF THE CONSULTATION EVENT TO
R.Devi@leeds.ac.uk

If there are any questions that you prefer not to answer then please leave these blank. We will use this information to describe in general who participated in the consultation discussion for this study. Please see our information sheet for further details.

About your role	
How would you describe your current role?	<input type="checkbox"/> Senior operational manager <input type="checkbox"/> Senior quality manager <input type="checkbox"/> Other, please specify:
How long have you been in this role (within both your current service and previous services)?	<input type="checkbox"/> Less than 1 year <input type="checkbox"/> 1 year – less than 3 years <input type="checkbox"/> 3 years – less than 5 years <input type="checkbox"/> 5 years – less than 10 years <input type="checkbox"/> 10 years or more
How long have you worked in the care home sector?	<input type="checkbox"/> Less than 1 year <input type="checkbox"/> 1 year – less than 3 years <input type="checkbox"/> 3 years – less than 5 years <input type="checkbox"/> 5 years – less than 10 years <input type="checkbox"/> 10 years or more
About your organisation	
What region(s) of England does your organisation cover?	<input type="checkbox"/> North West <input type="checkbox"/> North East <input type="checkbox"/> Yorkshire and Humber <input type="checkbox"/> West Midlands <input type="checkbox"/> East Midlands <input type="checkbox"/> Greater London <input type="checkbox"/> South West <input type="checkbox"/> South East <input type="checkbox"/> East of England

How many care homes are there in your organisation?	
What is the total bed capacity across the organisation?	
Do the care homes in your organisation provide nursing care?	<input type="checkbox"/> Yes, <u>all</u> of our care homes providing nursing care. <input type="checkbox"/> No, our care homes are residential homes without nursing. <input type="checkbox"/> The care homes in our organisation are a mix of residential and nursing homes.
How would you describe your organisation?	<input type="checkbox"/> For-profit <input type="checkbox"/> Not-for-profit <input type="checkbox"/> Other, please specify:
Equalities Monitoring Data	
Your Gender	<input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Prefer not to say
Your Ethnicity	<input type="checkbox"/> White English / Welsh / Scottish / Northern Irish / Irish / British <input type="checkbox"/> Asian / Asian British / Indian / Pakistani / Bangladeshi <input type="checkbox"/> Black / Black British / Caribbean / African <input type="checkbox"/> Other Ethnic Background - please specify _____ <input type="checkbox"/> Prefer not to say

Thank you for agreeing to take part in this consultation. It is very much appreciated.

We will only use your personal data for the purpose of reporting on the LESS COVID-19 Study. The information you have provided on this form will not be disclosed to any third party.

|

APPENDIX 3: PARTICIPANT INFORMATION SHEET (PHASE 1 INTERVIEW)

LESS COVID-19 (PHASE 1): Version 2 (22-05-2020)
Ethics ID: HREC 19-026



UNIVERSITY OF LEEDS

Participant Information Sheet – PHASE 1

LESS COVID-19

Learning by Experience and Supporting the Care Home Sector during the COVID-19 pandemic: key lessons learnt so far by health and care practitioners working on the frontline

You are being invited to take part in some important work. Before you decide whether or not to take part it is important for you to understand what this work is about and what will be involved if you decide you would like to take part. Read this information sheet carefully and if there is anything you want to discuss in more detail or that is unclear please contact the person named at the end. Take as much time as you need to decide whether or not you would like to take part. Your involvement is entirely voluntary.

What is the purpose of this work?

The COVID-19 pandemic is having a significant impact on the care home sector and, in particular, the older people living in these homes. The overall aim of this work is to capture the experiences of frontline health and care practitioners caring for older people with COVID-19 in hospital or care homes and to share the lessons learnt about the presentation, progression and management of the virus in this population with care homes that have not yet experienced it.

Who is completing this work?

This work is being led by the University of Leeds in partnership with the National Care Forum. We have the skills, expertise and contextual understanding to undertake this work and to develop resources for the care home sector.

Why have you been asked to take part?

We are asking frontline health and care staff caring for older people (aged over 65 years) with COVID-19 in hospital or care homes to take part. Your experiences are important to help us understand what care home colleagues need to know about caring for an older person with the virus. For example, this might include what you have learnt about presenting symptoms, progression of the virus, tipping points, or how best to manage virus symptoms or the care environment. By sharing what you have learnt you will help inform the development of valuable resources for the sector.

Do you have to take part?

No, it is entirely up to you whether you would like to take part or not. Your decision will in no way affect your work, and your organisation/manager will not know that you have taken part (unless you decide to tell them).

What is involved in taking part?

We are asking you to take part in one interview which will be conducted by video or telephone call (whichever you prefer) in your own personal time and at a time most convenient for you. We will ask questions about your experiences of caring for older people with COVID-19, in particular, what lessons you have learnt and would like to share with care home colleagues who may not yet have cared for an older person with COVID-19. The interview will take no more than 40 minutes: but you can advise on the time you can give to this work. If you agree to take part, we ask that you keep a copy of this information sheet and the consent form. With your permission, we will audio record the interview and written

notes will be taken to capture your experiences. Researchers in the team are experienced in conducting research with and for care homes.

If you are interested in taking part, or would like to discuss further, please contact Karen Spilsbury at the University of Leeds (contact details on last page). She will discuss the work with you and you will have an opportunity to ask questions. This discussion **does not** mean you have agreed to take part.

What are the benefits and risks of taking part?

This work is important to understand the lessons you have learnt, as a health or care practitioner, about caring for older people with COVID-19. What you share will be used to inform the development of resources for the care home sector and, in particular, for homes that may not yet have experienced COVID-19. Personally, you might find it useful to reflect on your work caring for this population. We do not consider there to be any personal risks to you taking part. However, we do appreciate that this may have been a very difficult period in your working life. Key resources to support the health and well-being of health and social care staff at this challenging time are provided at the end of this information sheet. It is entirely up to you whether you would like to take part in this work.

Can you withdraw at any time?

Even if you initially agree to take part, you are free to withdraw before or during the interview without giving a reason. If you choose to withdraw then we will not use any information that you have provided. If you withdraw at a later date (i.e. after the interview) then the information already collected from you will be included in our work unless we get this withdrawal within 1 week of the date you were interviewed. The reason for this is due to the timescales: we are trying to collate lessons learnt at pace for the care home sector.

Will the information you give be kept confidential?

Your personal information will be kept confidential and securely stored. With your permission, the interview will be recorded. You can decide whether you would like the interview to be conducted by video or telephone call. We will take written notes of your experiences and the lessons you have learnt. We will only use the recording to transcribe some of your words if it helps illustrate your point in the report of the work. You will not be identifiable in any reports from this work. You will be given a unique identification number (ID) and only researchers involved in the work will know your ID. This anonymised ID will be used when using any of your words (as illustrative quotes) in the report of findings. No personal information will ever be used. Everything you say or report in the interview is confidential unless you tell us something that indicates you or someone else is at risk of harm. In this situation we would have to disclose personal information. We would discuss this with you before telling anyone else.

The recordings of the interviews will be kept for 3 years, once data collection is completed, and then securely destroyed.

Who is responsible for handling any data collected for this study?

The University of Leeds is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this work and will act as the data controller for this work. This means that we are responsible for looking after your information and using it properly. We will keep identifiable information about you for 1 year after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the work to be reliable and accurate. If you withdraw from the study, we will keep information about you that we have already obtained.

To safeguard your rights, we will use the minimum personally-identifiable information as possible.

You can find out more about how we use your information at <https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf> or by contacting one of the researchers named at the end of this information sheet.

What will happen to the results of this work?

The main output of this work will be resources likely to have immediate impact for the sector. These resources will be made available online, in formats that can be downloaded by staff and providers, via a range of national web pages, for example, the National Care Forum (<https://www.nationalcareforum.org.uk/>), My Home Life (<http://myhomelife.org.uk/>), NICHE-Leeds (<https://niche.leeds.ac.uk/>). We will produce a written report and we plan to publish the results of this work to share the findings with as wide an audience as possible. We will produce a summary report for participants. If you wish to obtain a copy of the summary report, please let the researcher know. You will not be identified in any report/publication.

What if you have concerns about the study?

If you have any concerns or questions, or would like further details about the work, please contact Professor Karen Spilsbury (see contact details on last page).

Who do I contact if I wish to discuss a complaint about the study?

If you wish to discuss a complaint related to the conduct of this study please contact Clare Skinner (Head of Research Support, Faculty of Medicine and Health at the University of Leeds) by email governance-ethics@leeds.ac.uk or telephone 0113 343 4897.

Who is organising and funding this work?

This study is organised and run by the School of Healthcare at the University of Leeds, working in partnership with the National Care Forum. The work is funded for a 4-month period by the Dunhill Medical Trust and has been reviewed by the School of Healthcare Research Ethics Committee at the University of Leeds¹.

Thank you for taking the time to read this information sheet.

CONTACT DETAILS:

Professor Karen Spilsbury
School of Healthcare
University of Leeds
Baines Wing
LEEDS LS2 9JT

Email: k.spilsbury@leeds.ac.uk
Tel: 0113 343 1329
Twitter: @SpillersK

¹All projects carried out in the School of Healthcare must be reviewed and approved by the School's Research Ethics Committee before it goes ahead. Approval means that the Committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits, and that you have been given sufficient information on which to make an informed decision about whether to take part or not.

Resources to support the health and well-being of staff

We provide a summary of resources available to support the health and well-being of health and social care staff below. This summary is taken from the new guidance developed by the Department of Health and Social Care, which is available in full at

<https://www.gov.uk/government/publications/coronavirus-covid-19-health-and-wellbeing-of-the-adult-social-care-workforce/health-and-wellbeing-of-the-adult-social-care-workforce>:

Wellbeing support and building resilience

- Check in with team members regularly. It is important that connections with work and colleagues carry on for those working remotely or flexibly. Managers and employees should establish regular check-ins and try using video, when possible, to maintain face-to-face contact.
- [The British Psychological Society has put together a guide](#) aimed at leaders and managers that provides practical advice on how to respond to how staff may be feeling during difficult phases of working and living through the pandemic.
- Similarly, the [Local Government Association has put together some key steps](#) that they recommend employers take in order to support and protect the mental health of frontline staff at this time.
- The Tavistock and Portman NHS Trust in partnership with the Chief Social Workers of England have developed [guidance for the support and wellbeing of adult social workers and social care professionals](#).
- Employers can encourage their teams to create a [Wellness Action Plan](#) and encourage them to share these with line managers. This is a personalised and practical tool for employees to use to identify how to address what keeps individuals mentally well at work and what can result in poor mental health. It also opens up a dialogue, helping supervisors better understand the needs and experiences of employees.
- Registered managers can find [advice on maintaining team resilience on the Skills for Care website](#). It includes 2 guides. One gives examples of things that can be done to reduce workplace stress and the other provides examples and case studies of adult social care employers that have developed the wellbeing of their staff by building resilience.

Support for registered managers

- For registered managers, peer support is extremely important. Skills for Care has opened up its [members Facebook group](#) to other registered managers and frontline managers in similar roles. This is used to share advice, experiences and good practice.
- Similarly, [registered manager networks](#) can offer local support and are establishing WhatsApp groups to allow registered managers to stay in touch.
- [Skills for Care have also opened a new advice telephone line](#) (0113 241 1260) and email inbox (RMAAdvice@skillsforcare.org.uk) to provide registered managers with more support.

Support for those who work alone

- For home care workers, personal assistants and those working in isolated services, the nature of their work may mean that they already feel isolated. Skills for Care provides [guidance on how to support staff who regularly work alone](#). It includes a section on supporting mental health and wellbeing and on communication and support.
- This is in addition to Skills for Care's existing [guidance for people who employ their own staff and personal assistants](#), which includes where to find information about local support.

Other useful guidance

- To maintain the provision of good-quality care during the COVID-19 pandemic, it is essential that people who provide care and support can quickly and clearly communicate with primary care services, hospitals, community health services, local authorities, voluntary sector organisations, pharmacists and health services. There is [practical guidance from Digital Social Care](#) that has information on best practice for information sharing.
- [Digital Social Care has published lots of guidance and advice in response to the COVID-19 pandemic](#) on how technology can be used to support staff and the people they care for. They have also set up a new helpline to help providers access practical advice to troubleshoot a technical problem or give in-depth one-to-one support. The helpline is open Monday–Friday 9:00–17:00 and can be contacted either by telephone (0208 133 3430) or email (help@digitalsocialcare.co.uk).

APPENDIX 4: CONSENT FORM (PHASE 1 INTERVIEW)

LESS COVID-19 (PHASE 1): Version 2 (22-05-2020)
Ethics ID: HREC 19-026



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Consent form – PHASE 1

LESS COVID-19

Learning by Experience and Supporting the Care Home Sector during the COVID-19 pandemic: key lessons learnt so far by health and care practitioners working on the frontline

Before starting the interview the researcher will ask if you have read the participant information sheet (version 2, 22-05-2020) and that you understand and agree to the statements below. Please do not hesitate to clarify anything you are unsure about with one of the researchers prior to agreeing to these statements and taking part in the interview.

		Researcher to initial the boxes
1.	I confirm that I have read and understood the Participant Information Sheet dated 22-05-2020 (version 2). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. I agree to take part in an interview.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	
3.	I understand that any data collected may be looked at by individuals from the School of Healthcare (University of Leeds) where it is relevant to my taking part in this research.	
4.	I understand that even if I withdraw from the study, the data already collected from me will contribute to the study unless I withdraw within 1 week of the interview.	
5.	I understand that a copy of this Consent Form will be stored at the School of Healthcare, University of Leeds.	
6.	I agree for the interview to be audio-recorded and written notes to be taken during the interview as described in the information sheet.	
7.	I agree that anonymised quotes from the interview can be used in the final report of this work, and associated publications and presentations.	
8.	I understand that everything I say/report is confidential unless I disclose information that indicates someone is at risk of harm.	
	NAME (CAPITALS)	DATE
PARTICIPANT		
RESEARCHER		

APPENDIX 5: PARTICIPANT INFORMATION SHEET (PHASE 2 CONSULTATION)

LESS COVID-19 (PHASE 2): Version 3 (28-08-2020)
Ethics ID: HREC 19-026



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Participant Information Sheet – PHASE 2

LESS COVID-19

Learning by Experience and Supporting the Care Home Sector during the COVID-19 pandemic: key lessons learnt so far by health and care practitioners working on the frontline

You are being invited to take part in some important work. Before you decide whether or not to take part it is important for you to understand what this work is about and what will be involved if you decide you would like to take part. Read this information sheet carefully and if there is anything you want to discuss in more detail or that is unclear please contact the person named at the end. Take as much time as you need to decide whether or not you would like to take part. Your involvement is entirely voluntary.

What is the purpose of this work?

The COVID-19 pandemic is having a significant impact on the care home sector and, in particular, the older people living in these homes. The overall aim of this work is to capture the experiences of frontline health and care practitioners caring for older people with COVID-19 in hospital or care homes and to share the lessons learnt about the presentation, progression and management of the virus in this population with care homes that have not yet experienced it.

Who is completing this work?

This work is being led by the University of Leeds in partnership with the National Care Forum. We have the skills, expertise and contextual understanding to undertake this work and to develop resources for the care home sector.

Why have you been asked to take part?

We are asking care home senior operational or quality managers to take part in this Phase. We have already interviewed frontline health and care staff caring for older people (aged over 65 years) with COVID-19 in hospital or care homes. We will share these findings with you and explore with you strategies for managing COVID-19 at an organisational level within the home for the mutual benefit of residents, relatives and staff. Your contribution to this work is important: it will help us understand what colleagues need to consider when caring for an older person with COVID-19 in the care home environment. By sharing actual or potential strategies you will help inform the development of valuable resources for the sector.

Do you have to take part?

No, it is entirely up to you whether you would like to take part or not. Your decision will in no way affect your work, and your organisation will not know that you have taken part (unless you decide to tell them).

What is involved in taking part?

We are asking you to take part in one consultation event which will be conducted by video call on 3 September 2020 at 10:00-11:30. The consultation event will include other people in senior operational or roles in care home organisations.

We will share with you in advance of this consultation our findings from our interviews with frontline staff. The consultation will focus on asking you about whether the findings resonate with your experience and are useful for you and your organisation. We would like to explore

how the situation has developed and whether, in light of this, anything is missing from the report and in particular strategies you are using or think could be used for managing COVID-19 within the care home. The consultation will last 90 minutes (maximum). If you agree to take part, we ask that you keep a copy of this information sheet and the consent form. With your permission, we will audio record the consultation and written notes will be taken to capture the views and information shared by participants. Researchers in the team are experienced in conducting research with and for care homes.

What are the benefits and risks of taking part?

This work is important to understand the lessons you have learnt about caring for older people with COVID-19. What you share will be used to inform the development of resources for the care home sector and, in particular, for homes that may not yet have experienced COVID-19. Personally, you might find it useful to reflect on your work caring for this population. We do not consider there to be any personal risks to you taking part. However, we do appreciate that this may have been a very difficult period in your working life. Key resources to support the health and well-being of care staff at this challenging time are provided at the end of this information sheet. It is entirely up to you whether you would like to part in this work.

Can you withdraw at any time?

Even if you initially agree to take part, you are free to withdraw before or during the consultation without giving a reason. If you choose to withdraw after you have taken part in the consultation event, we would like your permission to use the recording, because this will contain the views of other participants. We will be able to omit your contribution. If you withdraw at a later date (i.e. after the consultation) then the information already collected from you will be included in our work unless we get this withdrawal within 1 week of the consultation date. The reason for this is due to the timescales: we are trying to collate lessons learnt and strategies at pace for the care home sector.

Will the information you give be kept confidential?

Your personal information will be kept confidential and securely stored. With your permission, the interview will be recorded. We will take written notes during this consultation of your actual or proposed strategies when managing care for older people with COVID-19 in your care home(s). We will only use the recording to transcribe some of your words if it helps illustrate your point in the report of the work. You will not be identifiable in any reports from this work. You will be given a unique identification number (ID) and only researchers involved in the work will know your ID. This anonymised ID will be used when using any of your words (as illustrative quotes) in the report of findings. No personal information will ever be used. Everything you say or report in the consultation will be heard by the other people taking part in the event. If you tell us something that indicates you or someone else is at risk of harm then we would have to disclose your personal information, and we would discuss this with you before telling anyone else.

The recordings of the consultation will be kept for 3 years, once data collection is completed, and then securely destroyed.

Who is responsible for handling any data collected for this study?

The University of Leeds is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this work and will act as the data controller for this work. This means that we are responsible for looking after your information and using it properly. We will keep identifiable information about you for 1 year after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the work to be reliable and accurate. If you withdraw from the study, we will keep information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information as possible.

You can find out more about how we use your information at <https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf> or by contacting one of the researchers named at the end of this information sheet.

What will happen to the results of this work?

The main output of this work will be resources likely to have immediate impact for the sector. These resources will be made available online, in formats that can be downloaded by staff and providers, via a range of national web pages, for example, the National Care Forum (<https://www.nationalcareforum.org.uk/>), My Home Life (<http://myhomelife.org.uk/>), NICHE-Leeds (<https://niche.leeds.ac.uk/>). We will produce a written report and we plan to publish the results of this work to share the findings with as wide an audience as possible. We will produce a summary report for participants. If you wish to obtain a copy of the summary report, please let the researcher know. You will not be identified in any report/publication.

What if you have concerns about the study?

If you have any concerns or questions, or would like further details about the work, please contact Professor Karen Spilsbury (see contact details on last page).

Who do I contact if I wish to discuss a complaint about the study?

If you wish to discuss a complaint related to the conduct of this study please contact Clare Skinner (Head of Research Support, Faculty of Medicine and Health at the University of Leeds) by email governance-ethics@leeds.ac.uk or telephone 0113 343 4897.

Who is organising and funding this work?

This study is organised and run by the School of Healthcare at the University of Leeds, working in partnership with the National Care Forum. The work is funded for a 4-month period by the Dunhill Medical Trust and has been reviewed by the School of Healthcare Research Ethics Committee at the University of Leeds¹.

Thank you for taking the time to read this information sheet.

CONTACT DETAILS:

Professor Karen Spilsbury
School of Healthcare
University of Leeds
Baines Wing
LEEDS LS2 9JT

Email: k.spilsbury@leeds.ac.uk

Tel: 0113 343 1329

Twitter: @SpillersK

¹All projects carried out in the School of Healthcare must be reviewed and approved by the School's Research Ethics Committee before it goes ahead. Approval means that the Committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits, and that you have been given sufficient information on which to make an informed decision about whether to take part or not.

Resources to support the health and well-being of staff

We provide a summary of resources available to support the health and well-being of health and social care staff below. This summary is taken from the new guidance developed by the Department of Health and Social Care, which is available in full at

<https://www.gov.uk/government/publications/coronavirus-covid-19-health-and-wellbeing-of-the-adult-social-care-workforce/health-and-wellbeing-of-the-adult-social-care-workforce>:

Wellbeing support and building resilience

- Check in with team members regularly. It is important that connections with work and colleagues carry on for those working remotely or flexibly. Managers and employees should establish regular check-ins and try using video, when possible, to maintain face-to-face contact.
- [The British Psychological Society has put together a guide](#) aimed at leaders and managers that provides practical advice on how to respond to how staff may be feeling during difficult phases of working and living through the pandemic.
- Similarly, the [Local Government Association has put together some key steps](#) that they recommend employers take in order to support and protect the mental health of frontline staff at this time.
- The Tavistock and Portman NHS Trust in partnership with the Chief Social Workers of England have developed [guidance for the support and wellbeing of adult social workers and social care professionals](#).
- Employers can encourage their teams to create a [Wellness Action Plan](#) and encourage them to share these with line managers. This is a personalised and practical tool for employees to use to identify how to address what keeps individuals mentally well at work and what can result in poor mental health. It also opens up a dialogue, helping supervisors better understand the needs and experiences of employees.
- Registered managers can find [advice on maintaining team resilience on the Skills for Care website](#). It includes 2 guides. One gives examples of things that can be done to reduce workplace stress and the other provides examples and case studies of adult social care employers that have developed the wellbeing of their staff by building resilience.

Support for registered managers

- For registered managers, peer support is extremely important. Skills for Care has opened up its [members Facebook group](#) to other registered managers and frontline managers in similar roles. This is used to share advice, experiences and good practice.
- Similarly, [registered manager networks](#) can offer local support and are establishing WhatsApp groups to allow registered managers to stay in touch.
- [Skills for Care have also opened a new advice telephone line](#) (0113 241 1260) and email inbox (RMAdvice@skillsforcare.org.uk) to provide registered managers with more support.

Support for those who work alone

- For home care workers, personal assistants and those working in isolated services, the nature of their work may mean that they already feel isolated. Skills for Care provides [guidance on how to support staff who regularly work alone](#). It includes a section on supporting mental health and wellbeing and on communication and support.
- This is in addition to Skills for Care's existing [guidance for people who employ their own staff and personal assistants](#), which includes where to find information about local support.

Other useful guidance

- To maintain the provision of good-quality care during the COVID-19 pandemic, it is essential that people who provide care and support can quickly and clearly communicate with primary care services, hospitals, community health services, local authorities, voluntary sector organisations, pharmacists and health services. There is [practical guidance from Digital Social Care](#) that has information on best practice for information sharing.
- [Digital Social Care has published lots of guidance and advice in response to the COVID-19 pandemic](#) on how technology can be used to support staff and the people they care for. They have also set up a new helpline to help providers access practical advice to troubleshoot a technical problem or give in-depth one-to-one support. The helpline is open Monday–Friday 9:00–17:00 and can be contacted either by telephone (0208 133 3430) or email (help@digitalsocialcare.co.uk).

APPENDIX 6: CONSENT FORM (PHASE 2 CONSULTATION)

LESS COVID-19 (PHASE 2): Version 3 (28-08-2020)
Ethics ID: HREC 19-026



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Consent form – PHASE 2

LESS COVID-19

Learning by Experience and Supporting the Care Home Sector during the COVID-19 pandemic: key lessons learnt so far by health and care practitioners working on the frontline

Before starting the [consultation](#) the researcher will ask if you have read the participant information sheet (version 3, 28-08-2020) and that you understand and agree to the statements below. Please do not hesitate to clarify anything you are unsure about with one of the researchers prior to agreeing to these statements and taking part in the consultation.

		Researcher to initial the boxes
1.	I confirm that I have read and understood the Participant Information Sheet dated 28-08-2020 (version 3). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. I agree to take part in one consultation event with the researchers and other participants.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	
3.	I understand that any data collected may be looked at by individuals from the School of Healthcare (University of Leeds) where it is relevant to my taking part in this work.	
4.	I understand that even if I withdraw from the study, the data already collected from me will contribute to the study unless I withdraw within 1 week of the consultation.	
5.	I understand that a copy of this Consent Form will be stored at the School of Healthcare, University of Leeds.	
6.	I agree for the consultation to be audio-recorded and written notes to be taken during the consultation as described in the information sheet.	
7.	I agree that anonymised quotes from the consultation can be used in the final report of this work, and associated publications and presentations.	
8.	I understand that everything I say/report is confidential unless I disclose information that indicates someone is at risk of harm.	
	NAME (CAPITALS)	DATE
PARTICIPANT		
RESEARCHER		