Healthcare experiences of care home residents during the Covid-19 pandemic

Survey report by Care Rights UK
13 July 2023
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**Introduction**

For more than three years, our organisation has offered support to people in care and their friends and family during the COVID-19 pandemic. During this time, we have seen the harm done as normal healthcare practices have been disrupted and neglected as the UK’s health and care system has responded to COVID-19. The full impact of this is difficult to overstate. We have seen many cases where people in care have been denied access to the healthcare that they need, their rights infringed as their physical and mental health suffered. We have supported family members in despair as they try to secure basic comfort and dignity for their loved ones. We know that many people have lost trust in a healthcare system which, they believe, has let them down when they most needed it. The findings of this survey report illustrate what we have been hearing on our helpline, week in and week out, from the very beginning of the pandemic.

The aim of the survey was to collect information on the healthcare experiences of people in care settings during the COVID-19 pandemic. A series of 26 questions were developed, drawing on the provisional scope for module 3 of the UK COVID-19 Inquiry. These questions focused on 5 key dimensions of healthcare:

- access to hospitals
- face-to-face appointments with healthcare practitioners
- visits out of care settings for healthcare appointments
- palliative and end of life care
- ‘do not resuscitate’ decisions

The first part of this report goes through these 5 areas in turn. Following this, the report will highlight 4 themes which emerged from the responses to the survey:

- the impact on physical and mental health
- difficulties with the use of remote communication
- the disruption of family involvement in healthcare
- problems with the training of care home staff for carrying out healthcare tasks

291 people participated in the survey and we received nearly 700 individual text responses. As much as possible, we have included full text responses from participants, so that the words of friends and family members can speak for themselves.

We would like to thank everyone who took the time to respond to the survey. For many of you, reliving the events of the past few years is a deeply painful task. The evidence provided in this report captures just some of the trauma and pain felt by those who struggled throughout the pandemic to secure the care that their loved
ones needed but were not receiving. The responses here provide vital evidence on the impact of the pandemic on access to healthcare services for people living in care homes. We hope that they will help to ensure that, as one survey respondent made clear, “this should never be allowed to happen to anyone else ever again”.
Key findings

1. More than 20% of respondents reported that the person in care was prevented from receiving treatment in hospital during the pandemic.
2. 69% of respondents reported that the person in care was unable to arrange face-to-face appointments with healthcare professionals including GPs, dentists, opticians, district nurses, physiotherapists, and chiropodists.
3. 177 respondents felt that the healthcare their loved ones received was made worse by restricted access to healthcare professionals during the pandemic (88% of those who responded to this question).
4. 35% of respondents who reported difficulties in accessing healthcare during the pandemic, and whose loved one is currently residing in a care home, reported that the person in care has still not resumed normal face-to-face appointments with all health professionals that they need to see.
5. Our survey demonstrates that the requirement that care home residents isolate on return from “high-risk” visits out, including a hospital stay, had a significant impact on many people’s decision making when it came to their or their loved ones’ healthcare, with 30% of respondents reporting that it affected decisions to access healthcare services outside of the care home.
6. Nearly 20% of respondents reported that the person in care had difficulty accessing palliative care professionals or end of life support during the pandemic.
7. Our survey revealed dozens of instances where people reported problems with Do Not Resuscitate decisions, including a lack of consultation and feeling pressured to make decisions which they were uncomfortable with.
8. Restrictions on access to healthcare during the pandemic had a significant impact on many care home residents’ physical and mental health, contributing to a range of worsening health conditions.
9. There were widespread problems with the use of remote communications technology in place of face-to-face contact with healthcare professionals, which affected the quality of healthcare that some people received.
10. Friends and family normally play an important role in the healthcare of care home residents. The disruption of this during the pandemic had adverse effects on people’s health and wellbeing.
11. Care home staff were often expected to take on new responsibilities as access to healthcare professionals was restricted. Staff did not always have the necessary training to fulfil these new roles well.
Accessing hospitals during the pandemic

More than 1 in 5 respondents to our survey reported that their loved one was prevented from receiving treatment in hospital during the pandemic, for reasons including a cancelled routine appointment or being denied an ambulance (table 1). These results reflect the findings of Amnesty International’s 2020 report on the UK Government’s failure to protect older people in care homes,1 as we can see that some care home residents’ access to NHS services, including hospital admission, were denied during the pandemic. 55% of respondents whose loved one was denied access to hospital felt that they were prevented from receiving treatment in a hospital because of their age or a disability (table 3). It appears that conflicting advice and confused decision-making contributed to multiple instances in which either a care home resident was not taken to hospital, or a person was advised that their loved one would not be taken to hospital if needed.

The responses to our survey highlight the wide-ranging impact of reduced access to hospital and healthcare services for older adults. Some respondents highlighted that cancelled or delayed appointments led to undiagnosed or misdiagnosed health conditions. Others explained that it contributed to worsening health conditions through delayed treatment, including the cancellation of surgeries and routine appointments. Delayed surgeries can lead to extended periods of pain and distress, and make it harder for patients to recover fully. While reports of care home residents being denied emergency care have been widely publicised, what is perhaps less well recognised is the long-term impact of delayed routine appointments and elective care. Data published by the Health Foundation in 2021 shows that 6 million fewer people completed elective care pathways between January 2020 and July 2021 than would have been expected based on pre-pandemic numbers.2 Responses to our survey demonstrate the impact that such delays can have on older people in care, such as an irrecoverable deterioration of health conditions including severely affected mobility.

What we were told:

“[The] home called 999, but kept family uninformed. Paramedics didn't convey to hospital because ‘of covid’. They said she would have been taken before the pandemic.”

“I was told no Gaps [sic] would be visiting, no resident would be admitted to hospital, no respiratory assistance would be given.”

“Disablement due to being left too long with severe covid before Dr insisted an ambulance was called, Care Home then tried to persuade Paramedic who attended the scene not to take relative who by that time was going into Sceptic Shock. Relatives life was saved but never regained mobility and was left Bedridden.”

“My father’s eyes deteriorated significantly when he couldn’t attend the eye clinic. He had numerous attendances at A&E due to kidney stones in his bladder, which meant he had regular blockages, which could not be cleared by his nursing home. He was due to have the kidney stones removed in April 2020, they were finally removed in September 2022.”

“They cannot grip a frame with one of their hands for transfer or to walk due to a neglected hand contracture caused by an upper arm fracture and nerve injury. They need surgery that has been cancelled and postponed multiple times and to this date there is no scheduled appointment. They had leg appliances fitted but waited a year for any input to enable them to start using them to stand or walk, this only just starting.”
Face-to-face healthcare

The restricted availability of face-to-face appointments with healthcare professionals during the COVID-19 pandemic had a profound impact on people’s health and wellbeing. 69% of respondents to our survey reported that their loved ones were unable to arrange face-to-face appointments with healthcare professionals including GPs, dentists, opticians, district nurses, physiotherapists, and chiropodists (table 4). Furthermore, almost 49% of those respondents reported that they were unable to arrange remote appointments (e.g. phone or video call) instead, highlighting a severe disruption of access to healthcare (table 5). Our survey suggests that, in some cases, this resulted in delayed diagnoses, treatment, and lead to adverse health outcomes. 177 respondents felt that the healthcare their loved ones received was made worse by restricted access to healthcare professionals during the pandemic (88% of respondents to that question, table 6).

One of the most significant consequences of restricted face-to-face appointments was the delay in diagnosing various health conditions. Early intervention is often crucial for successful treatment and management of various health conditions. However, without the ability to have thorough physical examinations and assessments, individuals will have experienced prolonged periods of uncertainty and anxiety regarding their health status. As will be discussed later in this report, remote communication methods, such as phone calls or video consultations, could not adequately replace the value of in-person contact, leading to suboptimal care delivery and limited therapeutic benefits. Furthermore, the lack of in-person contact with healthcare professionals led to delayed or deferred treatments for many individuals. Certain medical procedures and interventions simply could not be carried out remotely, and individuals were left to endure prolonged periods of discomfort, pain, or limited functionality without access to the necessary care. This resulted in avoidable suffering and a significant decline in the overall quality of life for affected individuals.

The most common healthcare professional which respondents were unable to arrange face-to-face appointments with were GPs (table 7). Many respondents told us that their GPs had stopped regular visits to care homes during the pandemic, relying instead on remote communication including phone calls and video calls. As will be discussed later, this often resulted in a range of problems and worse experiences of healthcare. A large number of respondents also reported a lack of face-to-face contact with dentists, opticians, physiotherapists, chiropodists, district nurses, and a range of other specialised healthcare professionals. It is important to note that more than one in three respondents who reported difficulties in accessing healthcare professionals during the pandemic, and whose loved one is still in a care home, said that they continue to struggle to secure access to healthcare professionals today (table 8). Our survey suggests that, in some cases, changes made during the pandemic have established themselves as the “new normal”, and that routine, in-person visits by healthcare professionals have not always returned to their pre-pandemic levels.
What we were told:

“I know with absolute certainty that Mum’s previous attendance at the specialist diabetic podiatry service maintained her good foot health. The absence of this (for more than a year) can only have had a negative effect on her. However, I was unable to view her feet due to care home closures. My calls to the care home and the podiatry centres failed to resolve the situation as I was frequently informed that visits from professionals were still not allowed. Eventually I was informed that the district nurses (who were subsequently allowed to visit care homes) would monitor Mum’s feet.”

“GPs had over the phone consultation, instructed care workers on how to do a GPs job, frustrating at best, dangerous at worst. No basic health care was carried out by professionals in any field, Hearing test, eye care, chiropractor, Gp visits, even the CQC didn’t venture inside for basic checks, Thank goodness my relatives was in good care homes who did their best.”

“Routine contact for residents by a GP in the care home we’re stopped. The surgery eventually employed a liaison nurse to visit regularly and this still contours [sic]. No GP visits regularly anymore. It’s not acceptable that residents cannot access readily a GP.”

“Access to health care via a GP is still limited & is unacceptable. I have managed to get a GP to visit my mother (also in a care home) twice when unwell but only by being very assertive.”

“Prior to the pandemic the GP would visit the home weekly, During the pandemic these visits stopped. Video only. Now to this day GP visits have not resumed.”
**Going to healthcare appointments**

Until August 2022, Government guidance on infection prevention and control in adult social care stated that care home residents should isolate on return from “high-risk” visits out, including a hospital stay. Our survey demonstrates that this restriction had a significant impact on many people’s decision making when it came to their or their loved ones’ healthcare, with 89 of 291 respondents reporting that it affected decisions to access healthcare services outside of the care home (table 10).

Many people reported facing a challenging dilemma as they had to weigh the risks of their loved ones going without healthcare against the harms of prolonged isolation. This balancing act could be particularly difficult for people supporting loved ones with dementia, who may have struggled to understand and contextualise the reasons behind their enforced isolation. In many cases, people felt that isolation would cause more harm than going without healthcare. Respondents were often clear in their view that the psychological and emotional toll of extended periods of isolation could be severe and have detrimental effects on the overall wellbeing of the person in care. For some, difficult choices had to be made between attending healthcare appointments, such as hospital visits, and maintaining connections with their family and friends. Several respondents made the decision to ask for no hospitalisation for minor falls, to avoid the person in care having to repeatedly spend extended periods of time in isolation.

In some instances, individuals opted to delay necessary treatments or procedures in order to prioritise the opportunity to see friends and family and attend important occasions, for example joining the family at Christmas, or attending birthdays or funerals. This decision to delay treatment could have direct consequences on their health and wellbeing, potentially leading to worsening conditions or missed opportunities for early intervention. However, such potential harms were often considered a lesser risk than the direct harm of isolation following a visit out for healthcare appointments.
What we were told:

“Mum did not see Gp face to face, therefore not examined. Tended to be seen by a paramedic. Often ended up being admitted to hospital and then having to isolate in room for 14 days after. This occurred a total of 7 times having a detrimental effect on her mental and physical health. I could not accompany her to these admissions/appointments”

“It was a huge worry, balancing Dad's need for treatment against the effect of isolation. Dad had Alzheimer's and didn't understand not being able to see family and became distressed when he felt "abandoned". Treatment had to be delayed so Dad didn't live half his life in isolation.”

“Massive impact on my mum, 2 weeks isolation after a hospital visit. After this she even didn't go to her sisters funeral as it would have meant another 2 weeks isolation, she hated it.”

“Mum delayed going for X-ray until after Xmas as she would have been isolated over Xmas 2021 for 14 days. She was in considerable pain and her mobility was affected.”

“It was very difficult to choose between essential healthcare for my father in law, and essential 1-2-1 interaction (eg personal visits, personal care) for him.”

“Fortunately we did not face this but it would have meant that had she needed healthcare, other than an emergency, I would have delayed or avoided treatment. No way would I have her endure self isolation on top of the months of separation from her family.”
Palliative and end of life care

Measures and restrictions introduced in response to COVID-19 had a significant impact on the delivery of palliative and end of life care. The responses to our survey paint a disturbing picture of the traumatic deaths that took place during the pandemic. Nearly 1 in 5 respondents reported that the person in care had difficulty accessing palliative care professionals or end of life support during the pandemic (table 11).

With visiting restrictions in place, family and friends had to rely on the care providers' assessment that their loved one was at the end of life before they were able to visit. It’s clear that there were issues with this, with some family members denied the chance to be with their loved ones in their final moments. The NHS emphasises that palliative and end of life care should enable someone to die with dignity. Our survey suggests that the integral role of family and friends in providing care and support at the end of someone's life was not always prioritised.

The survey also raises clear concerns around whether appropriate end of life care was taking place in instances where care providers were late in their assessment. Assessing and making decisions around end of life care can be difficult and requires training and support. Our survey suggests that some care home staff and medical professionals struggled during the pandemic, sometimes due to having to carry out assessments remotely. A number of responses to our survey reported that people in care received inadequate pain relief and monitoring towards the end of their life, contributing to unnecessary distress and suffering. As will be discussed later, our survey offers clear evidence that family and friends often play an important and under recognised role in care, including assessing when their loved one needs end of life care, and that this was disrupted by visiting restrictions during the pandemic.

3 https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/#:%7E:text=End%20of%20life%20care%20should,you%20to%20plan%20your%20care.
What we were told:

“Great distress to us both. Still upset by the memories of those difficult last months of her life. Not even allowed an end of life visit. The manager told me, ‘she’s close to the end of her life, but not quite there yet.’ On a video call my mum pleaded with me to visit. Video calls were very difficult as she couldn’t see or hear properly.”

“The GP was very reluctant to visit and the care home made no attempt to help my Mum obtain end of life care.”

“An unhappy and difficult death. Anguish for family. Lasting trauma.”

“Dad died without good end of life support. I experienced PTSD”

“Devastating impacts, no support to me as the person having to face such horrific circumstances alone and no support for my mum stuck in a room dying alone. The carers don’t have time for emotional support and especially when they were dealing with 22 other deaths in the rooms around them.”

“Staff believed my mum was end of life however, the GP refused face to face appointments and insisted on telephone appointments with the staff and put it down to her dementia progression. Eventually, the GP finally agreed to a video call to observe how my mum was presenting and within 5mins of the call agreed she was end of life and agreed to issue just in case end of life medication to the home. This process took weeks of the staff pleading with the GP to assess my mum visually as they knew she was end of life and needed palitive [sic] care and end of life medications issued.”
Do Not Resuscitate (DNR or DNACPR) decisions

Do-Not-Resuscitate (DNR) decisions serve as an important mechanism to honour the wishes of individuals in care and provide reassurance regarding their preferred end-of-life care. However, our survey findings unveiled significant issues surrounding the process of consultation on DNR decisions. In 2020, the Care Quality Commission (CQC) published a report that highlighted the pervasive problem of blanket decisions being made with regards to DNR. Our survey further highlights these concerns and brought to light specific challenges related to consultation on DNR decisions.

Notably, our survey revealed dozens of instances where people reported problems with Do Not Resuscitate decisions, including a lack of consultation with the individuals in care or their nominated relatives or friends holding lasting power of attorney for health and welfare (tables 13-15). This lack of involvement and discussion in the decision-making process raised significant ethical and legal concerns. In some cases, it was discovered after the fact that DNR decisions had been put in place without proper consultation, necessitating the challenge of these decisions.

Furthermore, respondents shared distressing experiences where they felt pressured or coerced into accepting a DNR decision for their loved ones. This coercion often stemmed from healthcare professionals or institutions, leaving family members and friends feeling marginalised and powerless in the decision-making process. The survey respondents expressed a profound sense of frustration and disappointment, as their wishes and the wishes of the individuals in care were disregarded. Respecting individual autonomy, facilitating open and honest communication, and involving designated representatives in the decision-making process, are essential to prevent inappropriate or coerced implementation of DNR decisions. Poor communication between healthcare professionals, individuals in care, and their designated representatives was a key factor in such instances of inappropriate or pressured implementation of DNR decisions.

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What we were told:

“It was explained to me that the NHS was too busy to cope during the pandemic so decisions were made to not actively keep someone alive if their age and condition meant the outcome would not be in the NHS's interests.”

“Coerced to comply.”

“I felt my brother was forced to sign documents with respect to my Mother.”

“Mum doesn’t have MCA. DNR put in place without my knowledge or permission-I am daughter.”

“Given my mother’s emaciated state, resucitaion [sic] would have broken her ribs. We agreed it would not be in her best interests to attempt it. However, what later became clear was that DNRS were being used as shorthand for "do not treat". This was my mother’s experience. The hospital put her on the palliative pathway within 2 days of her hospitalization against our wishes and LPoA. I had to go through the CoP to get my mother discharged home, where she lived another 14 months.”

“As mums next of kin it was a little confusing/unclear about when and where a DNR would be used, had i not been allowed to spend time with mum whilst she was in hospital i don't think i would have been consulted by the care home”

“Was advised this was in mums best interest in the first instance. Felt like I didn't know enough about it and just accepted I should do it. Felt guilty afterwards and wasn't sure I made the right decision.”

“Residents were just all prescribed anticipatory medication as routine and DNRS signed with no consultation with person or family, or LPOA or RPR.”
Key themes

Our survey received nearly 700 individual text responses from 291 participants. These responses offer a wealth of information and insight into experiences of healthcare during the pandemic. Through a process of coding and categorisation, we have highlighted four key themes which emerged from the survey.

Theme 1: Poor access to healthcare had a significant impact on people’s physical and mental health

Many respondents were clear in their view that changes to healthcare practices during the pandemic have had significant impacts on the physical and mental health of their loved ones. As has been established throughout this report, many care home residents were unable to access a range of important healthcare practitioners. For older people, missing routine appointments with healthcare practitioners such as audiologists, dentists, and opticians, can have significant impacts and make it harder for them to see, hear, communicate, and eat. A number of respondents highlighted how being unable to see physiotherapists and podiatrists contributed to a rapid loss of mobility. For older people, it can be extremely difficult to recover mobility, even if specialist support is available.

While these health issues might not be considered life threatening by themselves, they can contribute to deteriorating health which may lead to death. It’s also important to acknowledge that they can have a significant impact on a person's quality of life. The impact of health conditions which restricted people's ability to communicate with others, enjoy food, and move freely, must be considered in the context of COVID restrictions which disrupted normal routines in care settings and led to increased isolation. Taken together, the effects could be life changing.

The experience of declining health can have a serious impact on a person's mental health. What we can see from our survey responses is that this could be compounded by the inability to access appropriate treatment and support. Some people felt that they had been abandoned, that they would never be able to access treatment and get better. For others, worsening hearing, eyesight, and mobility, contributed to feelings of isolation and depression.

“I think when they had covid they just thought they were going to die and it was just sit and wait with no access to family or offers of any medical intervention. Their mental health certainly deteriorated massively as a result of this and isolation.”

“Mobility severely affected by a hip problem that was under control with physiotherapy but deteriorated significantly without the usual fortnightly sessions. Wheelchair bound now”

“It was distressing to see a loved one unable to eat because he had no dentures. The lack of hearing aids meant he couldn't communicate, it was difficult to maintain contact by telephone because he couldn't hear.”

“Physiotherapy was stopped, mobility declined and they lost the ability to stand to transfer. All transfers became by hoist, which is frightening and undignified. Loss of mobility has accelerated along with its associated health problems.”
Theme 2: Widespread problems with remote communications in healthcare

During the COVID-19 pandemic, many face-to-face appointments with healthcare practitioners were cancelled, and healthcare providers began offering phone calls or video calls to ensure continued access to healthcare services. The responses collected from a survey indicate that these forms of communication were often insufficient for delivering proper healthcare.

The responses to our survey suggest that phone or video calls do not allow GPs to carry out comprehensive assessments. Certain aspects of healthcare, such as physical examinations or hands-on procedures, require in-person interactions that cannot be effectively replicated through remote communication methods. Consequently, patients may have missed out on thorough assessments, potentially leading to incomplete diagnoses or delayed treatment plans. Without being physically present, some GPs relied on care home staff to carry out inspections, relaying instructions over the phone. When members of staff were not sufficiently trained, this could cause problems and potentially lead to a misdiagnosis. Similarly, relying on care home staff to pass on information could cause confusion and distress.

The use of remote assessments also exacerbated communication issues with patients, including individuals with speech or hearing impairments, or conditions such as dementia or Parkinson’s disease, for whom the use of communication technology proved challenging. These people may have struggled to express their concerns, provide accurate medical histories, or understand healthcare instructions during remote consultations.

“The day before she died, GP made assessment via 15 min Zoom call and deemed her settled despite my dad saying mum had been ‘very restless’ much of the day.”

“GP moved to online only in March 2020 and by the time Dad died in August 2021, the majority were still held online (only face to face for most severe illnesses/end of life). There was an impact on Dad’s physical health. e.g. in 2020 he had recurrent skin infections / cellulitis that were only escalated when family were able to visit (garden visit) and even from 2 metres away noticed his legs were weeping and infected; this resulted in complaints to care home and Dad nearly required an emergency hospital admission due to infection.”

“GP phone or video consultation, normally giving instructions over the phone to a carer to do blood pressure, or describe how a person looks, Frustrating and can lead to misdiagnosis.”

“The effect of Chinese whispers with care staff talking to the GP rather than the patient directly has meant prejudice and misunderstanding has reigned. Their needs have not been accurately or daringly addressed.”
Theme 3: Family and friends’ normal role in healthcare was severely disrupted

It is already widely recognised that families can and should play an important role in healthcare. The NHS promotes personalised care, emphasising the utilisation of the “expertise, capacity, and potential of people, families, and communities”\(^5\). The responses to our survey clearly indicate that friends and family members play a crucial role in healthcare, and the restrictions on visiting meant that they often couldn’t fulfil their usual responsibilities of monitoring the health and wellbeing of their loved ones. This lack of involvement had negative impacts on the health outcomes of the individuals in care. For example, family members are often in the best position to recognise signs of distress and discomfort, especially if the person in care is non-communicative. They have a deep understanding of their loved one’s unique needs and can also sometimes identify worsening conditions better than staff members who will not have the same long-term knowledge of the person and their condition.

In some cases, when friends and family gained access to their loved one they were able to identify evidence of poor care or treatment. Many respondents clearly feel that they have a role in monitoring their loved one’s health and ensuring that they receive high quality care. Some respondents were forced to seek further treatment and even emergency care for their loved one after periods of isolation. Many others reported only finding out about missing hearing aids or dentures when they were able to visit in-person. The survey highlights that family members are essential in monitoring health and wellbeing, and their absence during the restrictions had negative consequences on the individuals in care. Family members' familiarity with their loved one's condition makes them adept at identifying changes and providing valuable insights to the healthcare staff.

“my sister was being treated for cellulitis due to diagnosis via video link. Had I been going into care home as ‘normal’ her distress and obvious pain would not have gone untreated for the length of time it did”

“The lack of contact with family from March 2020-March 2021 had a huge detrimental impact on Dad’s physical health. We used to monitor his health closely and knew when he needed medical advice/attention: the care home staff were often not on the ball enough / too busy with the lockdown to know when to escalate Dad’s care to the GP and this led to a few serious incidents”

“My father’s toe nails were never cut from Oct 2020 until June 2021 and was given no access to a chiropodist despite me leaving funding for this at the home. I had no idea his feet were not attended to because I was visiting through glass and only got to see the shocking state of them when he attended a hospice appointment in June 2021. I moved him from this care home. He was self funding. The home blamed it on his dementia but if I would have taken him myself to a chiropodist if I had known.”

\(^5\) https://www.england.nhs.uk/personalisedcare/
Theme 4: Staff didn’t always have training to take on healthcare tasks

The loss of access to health professionals during the pandemic placed an immense additional burden on care home staff. Many of them will have responded heroically, going above and beyond their usual duties to provide necessary care and treatment to residents. However, the responses collected from our survey indicate that some care home staff were not adequately trained to handle the extra workload that was expected of them.

With the loss of routine appointments, check-ups, and face-to-face contact with healthcare professionals such as GPs, care workers were often left to take on the responsibility of diagnosing health conditions or triaging cases before accessing further care. Unfortunately, they were not always equipped with the necessary training and expertise to fulfil these roles effectively. This lack of training may have led to delays in identifying and addressing health issues, potentially compromising the well-being of the residents under their care.

Furthermore, care home staff were also tasked with providing treatments or offering continued support that would normally be administered by specialised healthcare professionals. These additional responsibilities stretched the capacity of care workers who may not have had the specific training and qualifications required for these specialised tasks. Several respondents highlighted issues when care home staff had to make end of life assessments; sometimes, these assessments failed to recognise that end of life care was needed until very late, meaning that appropriate treatment and medication wasn’t provided, and this sometimes also resulted in the person dying without their loved ones present. Our survey suggests that, in many cases, the quality of treatment and support provided may have been compromised due to the lack of expertise in certain areas.

“Poor knowledge/skills from care staff led to health issues going undetected—and not addressed. Eg. Severe weight loss, depression, toothache, broken spectacles. Equally no regular visits by district nurses/doctors and other health professionals had severe consequences on care home residents (and their families).”

“Care staff were unsupported in more complicated wound dressings, for example. Swallowing difficulties should have been professionally assessed in person, not over the phone.”

“The triaging by medically untrained care staff for access to zoom or telephone appointments with GPs or NPs was wholly inappropriate, most particularly for residents with dementia like my mother who were unable to communicate symptoms. They needed face-to-face examinations.”

“Care home staff were allowed to make decisions that medical professionals and families may not have made / agreed with if there had been suitable access to health care and as a result residents faced unnecessary suffering.”

“We were devastated to see the impact of lack of rehabilitation after mum’s stroke. Staff in the home did their best, but without access to trained physios etc, the outcome was never going to be good. It was heartbreaking to see her after the first lockdown ended. She was discharged from hospital when lockdown began so we weren’t able to access her room to help her settle in, and we were shocked at the change in her. It’s hard to talk about the situation without getting emotional.”
## Appendix

### Tables and charts

#### Accessing hospitals during the pandemic

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<table>
<thead>
<tr>
<th>Do you think that at any time they were prevented from receiving treatment in a hospital because of their age or a disability?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes: 34</td>
</tr>
<tr>
<td>No: 14</td>
</tr>
<tr>
<td>Not sure: 14</td>
</tr>
</tbody>
</table>

#### Face-to-face healthcare

<table>
<thead>
<tr>
<th>Table 4</th>
<th>Was the person in care unable to arrange face-to-face appointments with any health professionals during the pandemic?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes: 201</td>
</tr>
<tr>
<td></td>
<td>No: 46</td>
</tr>
<tr>
<td></td>
<td>Not sure / not applicable: 44</td>
</tr>
</tbody>
</table>
Table 5

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Not sure / not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Remote appointments</td>
<td>54</td>
<td>98</td>
<td>49</td>
</tr>
</tbody>
</table>

Table 6

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes, worse</th>
<th>No, same or better</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare</td>
<td>177</td>
<td>4</td>
<td>20</td>
</tr>
</tbody>
</table>

Table 7

<table>
<thead>
<tr>
<th>Health Professional</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>140</td>
</tr>
<tr>
<td>Dentist</td>
<td>104</td>
</tr>
<tr>
<td>Optician</td>
<td>94</td>
</tr>
<tr>
<td>District nurse</td>
<td>32</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>51</td>
</tr>
<tr>
<td>Chiropodist</td>
<td>93</td>
</tr>
<tr>
<td>Other</td>
<td>47</td>
</tr>
</tbody>
</table>

Table 8

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
<th>No longer in care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resume appointments</td>
<td>69</td>
<td>41</td>
<td>6</td>
<td>85</td>
</tr>
</tbody>
</table>

They are no longer in a care home: 85
Table 9
Which of the following health professionals has the person in care been unable to resume face-to-face appointments with?
- GP: 21
- Dentist: 10
- Optician: 9
- District nurse: 2
- Physiotherapist: 10
- Chiropodist: 3
- Other: 11

Table 10
Did the care home requiring self-isolation after visiting out affect any decisions to access healthcare services outside of the care home?
- Yes: 89
- No: 28
- Not sure / not applicable: 48

Table 11
Did the person in care have difficulty accessing palliative care professionals or end of life support during the pandemic?
- Yes: 53
- No: 69
- Not sure / not applicable: 169

Table 12
When did they have difficulty accessing palliative care professionals or end of life support? If this occurred more than once, tick all years that apply.
- 2020: 27
- 2021: 27
- 2022: 16
- 2023: 2
- Not sure: 2
### Do Not Resuscitate (DNR or DNACPR) decisions

Table 13

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was a ‘do not resuscitate’ (DNR or DNAPCR) decision made about the person in care during the pandemic?</td>
<td>127</td>
<td>1</td>
<td>40</td>
</tr>
</tbody>
</table>

Table 14

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
<th>No, they did not have the capacity to be consulted on this decision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were they consulted about this [DNR / DNACPR] decision?</td>
<td>20</td>
<td>21</td>
<td>6</td>
<td>80</td>
</tr>
</tbody>
</table>

Table 15

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
<th>They didn’t have a nominated person with Power of Attorney (LPA) for Health &amp; Welfare</th>
</tr>
</thead>
<tbody>
<tr>
<td>If the person in care had one or more nominated relatives/friends with ‘Lasting Power of Attorney’ (LPA) for their health and welfare, were those with LPA consulted about the decision for a DNR / DNACPR to be applied for the person in care?</td>
<td>79</td>
<td>17</td>
<td>4</td>
<td>27</td>
</tr>
</tbody>
</table>
About this research

This report summarises the findings of a survey conducted by Care Rights UK in April - May 2023. The aim of the survey was to collect evidence of care home residents’ experiences of healthcare during the pandemic, following the outline of module 3 of the UK Covid-19 Inquiry.

The survey was created using Google Forms and was disseminated through multiple channels to maximize participation. The survey was shared on Facebook and Twitter, sent via email to members and supporters of Care Rights UK, and other organisations in the sector were approached to share the survey with their respective mailing lists. 291 people responded to the survey between 27 April 2023 and 28 May 2023, and we received almost 700 text responses in total.

Once the data collection period concluded, the collected responses were exported from Google Forms and imported into Microsoft Excel for analysis. A combination of quantitative and thematic analysis techniques was employed to explore and interpret the survey data. A thematic analysis approach was employed to identify recurring themes, patterns, and insights within the qualitative responses. This involved systematically categorising and coding the open-ended responses to extract meaningful themes.

Acknowledgements

This report was written by Nicky Sharma, Policy and Research Officer at Care Rights UK. We would like to thank everyone who contributed to the design and distribution of the survey, including Alice Roberts, Kate Meacock, Jenny Morrison, Diane Mayhew, and Helen Wildbore.

We would also like to offer a heartfelt thank you to all those who responded to the survey and shared their stories with us.