Briefing: Adult social care and COVID-19

Assessing the impact on social care users and staff in England so far
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Key points

• The coronavirus (COVID-19) pandemic has had a profound impact on people receiving social care. As of July 2020, there have been over 30,500 more deaths among care home residents in England than we would normally expect. A further 4,500 excess deaths have been reported among people receiving domiciliary social care.

• While fewer domiciliary care users have died than care home residents, in proportional terms the increase in deaths has been higher in domiciliary care than care homes (225% compared with 208%). Domiciliary care users continue to die at a higher rate than has been reported in previous years. Many of these additional deaths have not been linked explicitly to COVID-19. It is unclear whether these additional deaths are due to the indirect impacts of the pandemic or as a result of undiagnosed cases.

• It is not just those receiving social care who have lost their lives during this pandemic. Social care workers are among the occupational groups at highest risk of COVID-19 mortality. Among this group, care home workers and home carers account for the highest proportion (76%) of COVID-19 deaths. We do not know exactly when these deaths occurred, so it is not possible to understand the extent to which more recent policy changes and infection control measures have improved safety for staff.

• COVID-19 outbreaks in care homes may be driven by multiple factors, including community transmission as well as infections picked up during hospital stays. Our analysis shows that between 17 March and 30 April, discharges from hospitals to care homes decreased in England to 86% of the historical average. 46,700 people were discharged from hospital to care homes between 17 March and 30 April – 7,700 fewer than previous years. The data available do not allow us to examine whether these discharges led to subsequent outbreaks in care homes.
• We found that while discharges from hospitals to residential care homes were 75% of the historical average, discharges from hospitals to nursing homes increased to 120% of the historical average.

• During March and April, similar to the general population, there was a substantial reduction in hospital admissions among care home residents. Elective admissions reduced to 58% of the 5-year historical average during this period and emergency admissions to 85% of the 5-year historical average. During this time, 14% of admissions had COVID-19 as the primary cause. By reducing admissions, care home and NHS teams may have reduced the risk of transmission. There may have also been an increase in unmet health needs but the data currently available do not allow us to assess whether this was the case.

• Long-standing structural issues have exacerbated the crisis in social care and hindered the response to the pandemic. But action is needed to prevent further harm, and this includes the need for data to fill the gaps highlighted in this briefing. Many of the most pressing data gaps concern domiciliary care, as it is not currently possible to track and understand the spread of infection in these settings. We also need more data on the health and care needs accumulated during the pandemic, and how well social care users are able to access essential services.

• The Health Foundation is undertaking a wider programme of work to improve social care data. Our work so far has pointed to deep-rooted structural and cultural challenges that impact how data are collected, shared and used. A new data strategy is needed for social care that first and foremost enables the provision of better care.
Introduction

The impact of the COVID-19 pandemic among those who rely on social care, and those working to care for them, is becoming clear. There have been more than 30,500 excess deaths in care homes alone during the pandemic in England. High rates of mortality among care home residents have been observed in multiple countries. Compared to 10 other European countries, residents of care homes in England and Wales account for a lower proportion of total COVID-19 deaths.* But when measured as a proportion of deaths of all residents in care homes, the UK has one of the highest proportions of deaths attributed to COVID-19 in comparison to 15 countries with equivalent data.†

The first confirmed case of COVID-19 was reported in the UK on 31 January 2020.‡ The SPI-M-O committee† provided a consensus view of the evidence (dated 16 March) that isolation of cases (and their households) and social distancing of vulnerable groups was unlikely to prevent critical care facilities in the NHS being overwhelmed.

On 16 March, the government announced strict social distancing measures for all, followed on 23 March by the Prime Minister’s televised address announcing additional measures (including the national lockdown).§ But UK figures on COVID-19 cases and deaths were initially not broken down by those receiving social care, either in care homes or the community. The number of COVID-19 outbreaks in care homes was first made public by Public Health England at the end of March, but the scale of the mortality only became clear as the Office for National Statistics (ONS) began to report place of death in April.¶ Until then, the alarm had been sounded in the media by those working in the sector.∫

In this briefing we give an overview of the impact of the COVID-19 pandemic on social care (as defined in Box 1) in England. In part 1 we describe how the pandemic unfolded in the social care sector from March until June 2020, and in part 2 we examine the factors that contributed to the scale and severity of outbreaks in care homes. In part 3 we attempt to quantify the disruption to health and social care access from February until the end of April 2020.

We use a mixture of national data sources from England, individual level data from the health care service, and publicly available data reported by Public Health England, Care Quality Commission (CQC) and ONS. We carried out novel descriptive analysis, with all code available and further description of the methods set out in the technical appendix‡ to this briefing.

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* Proportions have changed substantially since, but in May, this ranged from 26% in England and Wales to 66% in Spain, as reported in *Eurosurveillance* in a comparison of European/European Economic Area (EEA) countries: www.eurosurveillance.org/content/10.2807/1560-7917.ES.2020.25.22.2000956;jsessionid=3J2C0s4IvuDr3TVRh0h3b3Oq.i-0b3d9850f46b150f4-ecdc1ive#html_fulltext


‡ The technical appendix can be viewed at https://doi.org/10.37829/HF-2020-Q16
The impact of the COVID-19 pandemic in social care unfolded in a wider policy context. Issues such as what testing capacity was available, where resources were focused, and when government action was taken are essential to understand how the pandemic unfolded. These issues and the long-term neglect of social care, are addressed in Adult social care and COVID-19. Assessing the policy response in England so far. 

Box 1: The context of social care

<table>
<thead>
<tr>
<th>Settings:</th>
<th>Social care might be provided within the context of:</th>
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<tbody>
<tr>
<td>• care homes (residential or nursing care homes with 24-hour nursing available)</td>
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<tr>
<td>• domiciliary care (supporting an individual living in their own home)</td>
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<td>• day care or community care (such as community outreach and carers’ support).</td>
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Social care workers: Data on the social care workforce indicate that of the 1.62 million jobs in social care, 42% are in care homes, 42% are in domiciliary care and 15% are in community-based or day care services. These data do not include those who are self-employed as personal assistants. There are also approximately 8.8 million adults providing unpaid care in the UK. 

Social care users: There is a lack of accurate data on the number of people receiving each type of care. However, 842,000 individuals receive long-term support at any time of the year from local authorities. 35% of this group are younger adults (18–64 years old). Those receiving social care will often have additional support needs, health conditions, frailty, or disabilities that mean they need additional assistance with day-to-day living. Similar information is not available at a national level for those receiving domiciliary care. 

Paying for care: Care can be self-funded, but funding from local authorities is means-tested. Those receiving funding can elect to use direct payments to organise their own care. Therefore, care can be state or self-funded and state or self-organised. Those who self-fund and/or self-organise their care are often missing from much of the data on social care. In addition, a large number of adults receive unpaid care (in 2016, this totalled around 7.9 billion hours). Finally, there is significant unmet need – there are people with a need for social care who are not receiving it and there are little data available on this group.
Part 1: How did COVID-19’s impact on social care unfold?

In this section we track the course of the pandemic in England across social care, documenting the available evidence of the spread of COVID-19 and the impact it had on mortality among social care users and staff.

How did care home and domiciliary care outbreaks vary across England?

Public Health England data on care home COVID-19 outbreaks indicate that more than a third of all care homes had reported outbreaks by the end of April.\(^{13}\) This is not unexpected. Modelling work from academics that was considered by SAGE\(^{14}\) had indicated that without intervention, we could expect 75% of care homes nationally to have at least one outbreak.\(^{15}\) However, the national figure obscures substantial regional variation. Mirroring the spread in the wider community, London was initially the most heavily affected area, but outbreaks quickly spread. By June (and as shown in Figure 1), the north-east of England had the highest proportion of affected care homes at 54.2%.\(^*\)

Public Health England data track the number of new care homes reporting an outbreak and do not track the number of new infections in each care home over time in detail. While more detailed information is collected (Box 2), the publicly available data do not show if previously affected care homes are currently dealing with continued or new outbreaks, or whether infections have been successfully controlled.

Figure 1: Regional timeline of suspected or confirmed outbreak of COVID-19 in care homes by PHE centre (cumulative percentage)

Source: Health Foundation analysis of PHE data

\(^*\) Public Health England data available at time of writing cover the period to 28 June 2020.
Sparse and incomplete data mean that there is not enough information to understand whether the pandemic progressed in a similar way across domiciliary care. The CQC reports that from 2 to 8 May, approximately one-fifth of home care agencies were caring for at least one person with COVID-19. But these figures are not directly comparable with those from Public Health England on care home outbreaks (Box 2).

Box 2: COVID-19 outbreak reporting

Public Health England-reported care home outbreaks
Outbreaks in care homes are monitored by Public Health England, with local health protection teams responsible for making assessments and ordering COVID-19 testing. These data have been made public with weekly updates since 29 April 2020 and began on 9 March, when 33 care homes reported outbreaks.13

Care home capacity tracker
CQC-registered residential and nursing care home providers submit various data to the Capacity Tracker,17 including bed capacity, the number of COVID-19 cases, workforce absences and levels of personal protective equipment (PPE). The National Audit Office (NAO) estimated an average daily response rate of 29%. These data are not made public and we did not have access to them for this briefing.

Home care tracker
CQC-registered domiciliary care providers submit various data to the Home Care Tracker,18 including the number of people using services, the number of COVID-19 cases, workforce absences and PPE levels. Data collection began on 13 April and the NAO estimated an average daily response rate of 52%. The tracker only covers regulated organisations and not individuals providing care. Again, these data are not made public.

Having detailed data available on how outbreaks have occurred across different social care settings would allow local public health teams to identify areas of high infection risk and ensure that infection control measures (such as lockdowns, adequate PPE supply and COVID-19 testing) can be put in place. It would also enable the local coordination of efforts across services to reduce the spread of infection among support staff, those receiving care and their loved ones during the outbreak.

The total mortality in the care home sector so far

In England, the first recorded deaths from COVID-19 in care home residents occurred on 6 March 2020. Figure 2 shows deaths in care homes reported to CQC over time. By 19 June there were 17,736 notifications of deaths involving COVID-19 among care home residents,19 almost 40% of all COVID-19 deaths in England.20*

* ONS data – sources vary by the cut-off date for death registration; 20 June for care home resident deaths and 27 June for deaths in the whole population.
During the same period, there was also an increase in total excess deaths among care home residents. Excess deaths are additional deaths, compared to the number usually expected at that particular time of year. Between 23 March and 19 June 2020, there were more than 30,500 excess deaths in care homes (208% of the deaths seen in previous years). 19,800 of these excess deaths (compared to data from 2017–2019) were not recorded as linked to COVID-19.

As excess deaths include mortality where COVID-19 was not recorded, as well as deaths where it was, they are considered a more appropriate estimate of the total likely impact of the pandemic on mortality. The excess deaths reported in this period may include undiagnosed COVID-19 cases, particularly if testing was not easily accessible. But these deaths may also result from indirect effects of the pandemic. The impact of isolation, reduced social care services and difficulty in accessing health care may well have contributed to the excess mortality. The reduction of non-COVID-19 linked deaths by early May might indicate COVID-19 cases were being better identified as such, or that the indirect impacts of the pandemic were being more successfully addressed. By 19 June, deaths from any cause continued to fall and had returned to the levels usually observed at this time of year. 19
The total mortality among those receiving social care in their homes

While deaths of people living in care homes have hit the headlines, the situation among those receiving domiciliary care has received much less attention. The first COVID-19 death notifications of those receiving care at home were recorded with the CQC on 10 April. By 19 June, the CQC had received notifications of a total of 819 COVID-19 deaths in domiciliary care.

But deaths were rising among people receiving domiciliary care even before 10 April, as shown in Figure 3. Between 23 March and 19 June, the number of death notifications to CQC was 225% of the number seen in 2017–2019 – an estimated 4,500 additional deaths. While the absolute number of deaths reported in domiciliary care is smaller than in care homes, the proportional increase is greater. In addition, although the number of deaths linked to COVID-19 in domiciliary care has reduced over time, as of the end of June, excess non-COVID-19 linked deaths remained in excess of what has been reported in previous years.

Figure 3: 7-day rolling average of deaths reported to CQC of home care service users (by date reported, up to 19 June 2020)

Understanding the reasons for these excess deaths where COVID-19 has not been recorded is critical. If these deaths are linked to COVID-19 infection, but not recorded as such, then it raises questions about the adequacy of COVID-19 testing programmes in social care. It also means that the spread of infection among those receiving social care in the community has been underestimated. If the deaths have been correctly coded, and are linked to indirect effects of the pandemic (such as delayed access to health or care services), then this would mean that urgent action is needed to address this unmet need.
It is worth noting that other factors may have contributed to increases in death notifications from care providers. For example, given an overall decrease in hospital admissions in the population, deaths are more likely to have occurred at home instead of in hospital during this period, and therefore reported by domiciliary care providers.

The CQC only collects information on deaths from registered and regulated organisations providing social care at home and in the community, therefore omitting individual self-employed carers. Organisations are only required to report deaths that occurred while a regulated activity was being provided or may be a result of that regulated activity. This means that it is likely that CQC’s figures significantly underestimated the true impact of the pandemic on people receiving domiciliary care. Also, deaths may not have been reported to CQC when care was suspended due to lockdown measures, where care was not routine or frequent, or where care was suspended for other reasons, such as a hospital admission. The data collection methods also omit deaths from those receiving care from self-employed or unpaid carers.

**Do social care users from more vulnerable groups have a higher risk of death?**

COVID-19 does not affect all people receiving social care equally. CQC has noted high numbers of death notifications (across all types of care providers) for people with learning disabilities21 and those detained under the Mental Health Act.22 It has also raised potential concerns about a disproportionately high number of deaths among social care recipients from minority ethnic groups, particularly black adults.23 Further work is needed to understand the reasons for these deaths and identify if there are other individual characteristics or features of care provision linked to greater risk so that appropriate protections can be put in place.

**Excess mortality among social care staff**

It is not just those receiving social care who have lost their lives during this pandemic. ONS published analysis of data from both England and Wales (covering 9 March to 25 May 2020), showing significantly raised COVID-19 death rates among those working in social care (managers, nurses and social care workers, care home workers and home carers).24 ONS highlights that in this group, care workers and home carers account for the highest number of COVID-19 deaths (76%, or 204 of 268 deaths).1 We do not know exactly when these deaths occurred, so it is not possible to understand the extent to which more recent policy changes and infection control measures25 have improved safety for staff.

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* Self-employed carers are poorly captured by current data sources, but Skills for Care estimates that 75,000 individuals receiving direct payments employ their own staff. The number of people paying for self-employed carers through self-funding or other funding streams is unknown.

† Figures include staff aged 20–64 years old; deaths among staff older than 65, who are likely to be at higher risk, are not represented.
Part 2: The vulnerability of care homes to COVID-19 outbreaks

In this section we focus on care homes. There has been debate as to the root causes of the mortality seen among residents during the pandemic. The vulnerability of a care home to an outbreak of the virus will depend on the risk of introduction, transmission and the susceptibility of residents to severe infection. Here we consider what the available data tell us about the likely contribution of each of these.

Unfortunately, available data do not allow us to assess potential COVID-19 infection risks within domiciliary care. Further research and analysis are needed, given the specific problems that the domiciliary care sector experienced in accessing COVID-19 tests and PPE.

The risk of introducing COVID-19 into care homes from hospital or the community

COVID-19 may be introduced into care homes by staff, visitors and residents. Evidence is still emerging as to the relative importance of each of these potential routes. Directors of adult social care services have raised major concerns that hospital discharges may be a source of introducing COVID-19 into care homes.\(^\text{26}\) Evidence to date has highlighted that staff may have been an unwitting source of infection, particularly when working as bank or agency staff, or where sick pay was not available.\(^\text{27}\)

To assess the scale of any possible introductions from hospitals to care homes due to discharges, we carried out novel analysis of individual patient data from all hospitals in England up to 30 April 2020. Due to poor recording, hospital data alone will underestimate care home residency by as much as 70% (from our estimates). Therefore, an additional algorithm developed by the Health Foundation was used to identify patients who were residents of care homes. This matched the address registered with a patient’s GP to care homes registered with CQC. Full details of the methods, which have been previously validated, are described in the technical appendix.\(^\text{\*}\)

In February 2020, this captured data from 355,907 people living in care homes in England.\(^\text{†}\) Of these, 80.2% were older than 65 years and 44.5% were identified as living in nursing homes, as opposed to residential care homes. Using this linked dataset, we estimated the number of hospital discharges of new and permanent residents to care homes in England.

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\(^\text{†}\) This underestimates the true population of care home residents.
Hospital admissions and discharges were higher than historical averages for residents of care homes and the general population in January and February 2020. During February, discharges to care homes were 9% higher than the historical 5-year average across 2015–2019 for this period – see Figure 4. There were 46,700 discharges to care homes between 17 March and 30 April, the period after NHS England and NHS Improvement had issued measures stating that medically-fit patients should be discharged and elective procedures limited.\textsuperscript{28,29} However, this is 86% of the average number of discharges usually seen at that time of year (as shown in Figure 4). As can be seen from the pattern of admissions in the same figure, this drop may be due to the smaller number of patients being admitted to hospitals (following the measures already mentioned). Hospital admissions for care home residents fell to around 70% of the historical average across this period. But the pattern varied between care home types. While discharges to residential care homes fell to 75% of their historical average (12,400 discharges), discharges to nursing homes actually increased to 120% of the historical average (17,000 discharges).\textsuperscript{*}

Without additional data on testing and the spread of infection among individuals, it is not possible to robustly quantify whether and how much these discharges contributed to the spread of the virus. However, some of these discharges could have represented an infection risk, particularly in March and early April. At this time, testing for COVID-19 was not recommended prior to discharge from hospital. Without testing it is unlikely that asymptomatic or presymptomatic patients would have been identified, and appropriate isolation measures adopted, to prevent onward transmission in the care home. In any case, there is evidence that care homes struggled to access PPE and implement isolation measures,\textsuperscript{30} which will have increased the risk of spreading infection from any COVID-19 positive patients discharged to their care. There is evidence that where a care home had at least one detected case, higher staff levels and more severe PPE shortages were most linked to higher case counts.\textsuperscript{†} Measures introduced in the Coronavirus (COVID-19): adult social care action plan, to test all residents prior to care home admission, should reduce the risk of infection from patients being discharged from hospital.\textsuperscript{31}

\textsuperscript{*} Note that 17,300 discharges were to care homes of unknown type.

\textsuperscript{†} From a study of 248 care homes in Norfolk: www.medrxiv.org/content/10.1101/2020.06.17.20133629v1
Our analysis may underestimate the number of hospital admissions towards the end of April. This is because data for patients who are still in the hospital by the end of the reporting period might not be included. Sensitivity analysis that limits the analysis to hospital spells with a duration of less than 45 days can be accessed via GitHub https://github.com/HFAnalyticsLab/COVID19_care_homes
Infections can also be introduced into care homes from visitors or care staff, who without testing may unknowingly transmit infection as they move from the community into and across care settings. 7% of care home staff have tested positive for COVID-19 since the start of the pandemic up to 19 June. In previous Health Foundation analysis, we found that in many areas of the country the scale of the outbreaks in care homes mirror that in the general population. International comparisons have also found that the total proportion of care home residents who have died due to COVID-19 closely follows the deaths attributed to COVID-19 per 100 million.

**Risk of transmission within care homes**

Due to care needs, residents require close personal contact with others on a frequent basis. During the early stages of the pandemic in England, evidence emerged from other countries (such as the USA) about the importance of asymptomatic infection, and that COVID-19 may present atypically in patients who are older or have dementia. In the UK, the initial guidance was to test and isolate only those who were symptomatic (with ‘conventional’ symptoms). As a result, some positive cases in care homes may not have been correctly identified and isolated, increasing the risk of transmission. It was not until 3 July that the government committed to testing all staff in care homes regularly. National figures on the number of cases among care home workers only began to be reported on 16 July. However, the important role that staff play in transmitting COVID-19 has been observed in several research studies, with both symptomatic and asymptomatic transmission taking place. This includes early findings from a large national survey of care homes (the Vivaldi study), which showed a significant correlation between infection rates among staff and infection rates among care home residents. Regular testing, now recommended by government guidance for all care home staff, allows symptomatic and asymptomatic staff to self-isolate and prevent transmission to residents.

**The susceptibility of residents to severe infection**

In our analysis of the care home population, we found that in February 2020 permanent care home residents were of advanced age (80.2% were older than 65 years), and unsurprisingly living with chronic conditions. 40% of residential home residents and 48% of nursing home residents were living with dementia; 13% of care home residents and 17% of nursing home residents had diabetes; and 13% of care home residents and 15% of nursing home residents had chronic obstructive pulmonary disease. These figures are likely to underestimate the true prevalence of these conditions, as the information was taken from hospital records for residents, which can incompletely record chronic conditions on admission. If a resident did not have an inpatient admission, it was not possible to determine if they had any of these conditions. Nevertheless, these numbers highlight the fact that residents are admitted to care homes because of advanced age and increased need for additional care and assistance.

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* Dementia was measured as defined under the frailty index and uncomplicated diabetes and chronic obstructive pulmonary disorder were measured as defined by code lists under the Elixhauser Score. All long-term conditions were measured using diagnosis codes from hospital admissions over the previous 3 years.
This makes residents particularly vulnerable to COVID-19 when infected. The risk of severe illness and death due to COVID-19 has been closely linked to frailty and underlying illness such as dementia, diabetes, chronic respiratory disease and a range of other chronic conditions. Therefore, if there is an outbreak of COVID-19 in a care or nursing home it is likely that residents would be at high risk of severe illness or mortality. Findings from the limited number of studies with detailed information on outbreaks in care homes support this, reinforcing the need to shield and protect residents from infection.
Part 3: The availability of essential health and social care services during the pandemic

In both health and social care, services have been reconfigured rapidly to control infections and respond to staff absences. In this section, we present what the data are telling us about the availability of some health and care services during the pandemic. Unfortunately, we have too little data about the impact of these changes on people using social care to take a comprehensive view of the impact.

Changes in access to social care services

There are limited robust data on how the pandemic, and the responses from local and national government, have affected access to social care. Data on the capacity of social care providers have not been made public (see Box 2), but Skills for Care has reported that staff absences have risen. It should be noted that these issues not only affect organisations providing care, but also individuals or families who directly employ carers. The burden is often falling on unpaid carers to cover the gap.

There are also limited data on how the demand for social care has changed. 26% of care providers reported an increase in demand for social care in May, however, 46% reported a decrease. This reduction in demand for services is particularly worrying in the context of significant unmet and under-met social care needs that pre-date the pandemic. Falling demand for care may be driven by concerns among people needing care, or their families, about the infection risk.

Changes in access to hospital services for care home residents

Due to lack of available data from domiciliary care recipients, and data from primary and community care, we have focused this section on changes to hospital care among care home residents.

During the pandemic, various measures were introduced to reduce the risk of spreading infection, and ensure hospitals had capacity to deal with COVID-19 cases. NHS England and Improvement requested that all non-urgent elective operations were postponed from 15 April for a period of at least 3 months. These were then requested to resume, in a letter dated 29 April.

Through carrying out novel analysis of all hospital admissions in England (the methods for identifying care home residents are described in part 2 and the technical appendix), we can show that hospital admissions from care homes were higher than the historical average before the pandemic. Admissions then decreased to 79% of the historical average, corresponding to 11,800 fewer admissions during March and April. In this period, admissions from care homes to hospital rose as a share of all hospital admissions (Figure 4) and 6,200 of admissions from care homes (14%) had COVID-19 listed as the primary diagnosis. Admissions from residential care homes decreased more substantially for the same period to 73% of the historical average (6,700 fewer admissions), while admissions from nursing homes only fell to 91% (2,000 fewer admissions).

* 16.4% of care homes could not be categorised as residential or nursing homes; admissions fell to 70% for this unknown group.
Unsurprisingly, elective admissions dropped more dramatically (to 58% of the 5-year historical average, equivalent to 5,300 fewer admissions) than emergency admissions (to 85% or 6,500 fewer admissions).

The context for these changes is complex, as there have been substantial shifts in how health care is provided during the pandemic. For example, guidance was issued to care homes about how to support residents who require hospital care, and primary and community care teams were advised to conduct weekly check-ins, examine patients and facilitate the supply of medication. Some care needs therefore may have been met by these additional measures. Previous analysis by the Health Foundation has shown that avoidable emergency admissions can be reduced through enhanced primary care in care homes. Infection risks in hospitals may have also affected decisions around care during this period. For example, care delivered by primary or community care, or staff in care homes, may have been preferable to a hospital admission during this period.

Nevertheless, these data highlight that there may be substantial unmet health needs among care home residents for elective care. Further research is needed to quantify the impact, if any, on mortality and other outcomes, which will need to be addressed as the system moves into long-term planning.
Discussion

In this section we discuss what our analysis means for social care as the country prepares for potential future waves of infection.

Understanding and tackling excess mortality among social care users

In addition to more than 30,500 excess deaths of those living in care homes during the pandemic, our analysis has shown that there has been significant loss of life within the domiciliary care sector, with mortality increasing by 225%. As of July, new infections and outbreaks in the general population and care homes have declined from their peak at the end of April. But deaths among those receiving domiciliary care have remained persistently above the average seen at this time of year.

Policies to tackle outbreaks of COVID-19 in care homes have been announced. The government has outlined a risk reduction framework for social care and introduced an adult social care infection control fund. However, further research is needed to understand the root cause of excess deaths among those receiving care in the community. This will be helpful to guide specific action to address excess mortality now and during any future waves.

The causes of outbreaks in social care

COVID-19 outbreaks in care homes may be driven by multiple factors, including transmission in the community, which will affect the prevalence of the virus among care home staff and visitors, as well as infections picked up during hospital stays. In relation to hospital stays, our analysis shows that between 17 March and 30 April discharges from hospital to care homes decreased in England to 86% of the historical average. Patients would have been discharged when judged medically fit to do so by a clinician. It has been highlighted that this would have been done in good faith and in the belief that the hospital was no longer an appropriate place for their care.

The reduction in discharges appears to have been driven by a reduction in the number of people admitted to hospital, which fell substantially from March onward. Nevertheless, 46,700 people were discharged from hospital to care homes between 17 March and 30 April, 7,700 fewer than previous years. The data available do not allow us to examine whether these discharges led to subsequent outbreaks in care homes. Further research is urgently needed, particularly in nursing homes where discharges from hospitals have increased.

Tackling unmet need for health and social care services

Our analysis pointed to substantial disruption to health care for care home residents, with reduced emergency and elective admissions. By reducing admissions, care home and NHS teams may have reduced the risk of transmission. There may have also been an increase in unmet health needs. Unfortunately, the data available do not allow us to assess whether

* David Oliver, consultant in geriatrics and internal medicine notes: ‘I believe that some of the now clearly mistaken decisions in local services about care homes were made in good faith, in novel and urgent contexts.’– www.bmj.com/content/369/bmj.m2334
this was the case. Further analysis is needed, including data on wider community care, primary care and mental health. There may also be medium and long-term health needs for social care users, workers and their families, due to indirect effects like isolation during the lockdown. As the NHS attempts to restart care that was disrupted during the first wave of the pandemic, the needs of social care users and care home residents should not be overlooked.

**Addressing the long-term structural issues in social care data, funding and provision**

As the Health Foundation’s briefing *Adult social care and COVID-19: assessing the policy response in England so far* highlights, the COVID-19 pandemic has exacerbated and amplified many of the longstanding issues within social care. These include issues with long-term underfunding of the sector, a deep staffing crisis with high vacancy rates, a complex and fragmented organisational structure and a problematic lack of data.

As illustrated by this briefing, there are key gaps in the information that is collected, particularly outside the care home system. Through the patient and public involvement we carried as part of our research, it was clear that the available data contain large gaps in capturing the needs of those receiving care, particularly in areas such as mental health or the impact of unmet social care needs on wellbeing.

There are particular challenges in how data are collected, shared and used in social care. For example, some care providers may be reluctant to share data for fear of the consequences on their finances, and the data collected may not focus enough on how care can empower users to live independent lives. Most datasets collect information about care from provider organisations, which omit care provided by individuals (paid or unpaid). Addressing these problems will require a new data strategy for social care with the primary objective of improving the quality of care. Such a strategy needs to come with investment so that the data collected can be used to improve care, for example by establishing better data infrastructure to enable real-time analysis, building skills in analysis, and fully incorporating the lived experience of users into the interpretation and use of the analysis.

Better person-level data on staffing, social care capacity, testing and health care and social care provision are needed to better prepare for subsequent waves of COVID-19, and would also bring long-term benefits. During the pandemic, we have seen how valuable health data have been in enabling new treatments and supporting innovation, such as via the RECOVERY trial. With further investment, similar innovations are possible within social care.

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* We spoke to five people who, during the COVID-19 pandemic, had interacted with social care services either for their own care needs or the care needs of a loved one. We listened to their experiences and their perspectives on the crisis and the data presented in this briefing.

Conclusion

The COVID-19 pandemic has been felt hardest among those who rely on social care, and those working to care for them. The death toll during March and April 2020 alone was devastating. The impact on the health and wellbeing of care workers and unpaid carers may take time to become visible, and may be profound.

Our briefing shows the scale of the challenge of keeping people who need social care safe and in providing high-quality health and social care during the pandemic. It also indicates the speed of action required to tackle transmission and prevent loss of life among a particularly vulnerable group.

As England begins to plan beyond the immediate crisis, it is critical that the issues highlighted here are urgently addressed to prevent further harm.
References


Acknowledgements

We are grateful to Annemarie Naylor from Future Care Capital for her comments and to members of the public who took the time to participate in structured discussions, reviewing our findings, sharing their thoughts and experiences during the pandemic, and helping to improve this work. Likewise, thanks go to Adam Steventon, Jennifer Dixon, Hugh Alderwick and Phoebe Dunn for their helpful comments on previous versions of this briefing and to the DA COVID-19 working group who provided feedback throughout the project. This work uses data provided by patients and collected by the NHS as part of their care and support.

When referencing this publication please use the following URL:
https://doi.org/10.37829/HF-2020-Q16