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The COVID-19 Long-Term Care situation in England

Adelina Comas-Herrera, Alan Glanz, Natasha Curry, Sarah Deeny, Chris Hatton, Nina Hemmings, Richard Humphries, Klara Lorenz-Dant, Camille Oung, Selina Rajan, Aida Suarez-Gonzalez

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Authors

Adelina Comas-Herrera, Klara Lorenz-Dant and Alan Glanz: Care Policy and Evaluation Centre, Department of Health Policy, London School of Economics and Political Science

Natasha Curry, Nina Hemmings and Camille Oung: The Nuffield Trust, London

Sarah Deeny: The Health Foundation, London

Chris Hatton: Manchester Metropolitan University

Richard Humphries: The King's Fund, London

Selina Rajan: The London School of Hygiene and Tropical Medicine

Aida Suarez-Gonzalez: University College London

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@adelinacohe @NatashaCurry123, @sarahdeeny, @NinaHemmings92, @RichardatKF, @LorenzKH, @selinarajan, @Aida_Suarez_, @CamilleOung, @CPEC_LSE, @HealthFdn, @NuffieldTrust

Key points

- The impact of the COVID-19 pandemic has been severe in England and has affected disproportionately people who use and provide long-term care.
- Since the beginning of the pandemic and until the 6th November, 15,659 people had died in the care home and their deaths were linked to COVID-19 in the death register. An estimate of the deaths of care home residents (including those who died in hospital) suggests that, until the 13th November, 20,799 care home residents died whose deaths were attributed to COVID-19. An estimate of excess deaths in care homes suggests that 22,948 more people died until the 30th October, compared to the previous 5 years. This would represent around 5% all care home residents.
- There have also been increased deaths among people receiving care at home, people who work in social care provision, and the people with learning disabilities and dementia.
- The initial COVID-19 policy responses did not adequately consider the social care sector. A social care action plan was not introduced until mid-April, almost a full month after the Prime Minister announced the country would go into lockdown.
- With the response almost entirely focused on the NHS, too little consideration was given to the fragmented social care system, which was already in a fragile state prior to the pandemic, and into which many people were being discharged from hospital. Delays in access to personal protective equipment and staff and service user testing are likely to have contributed to the high death toll in the sector.
- Since the first wave, there has been improvement in terms of availability of guidance, access to Personal Protection Equipment and testing.
- In the second wave, care providers continue to face challenges with testing capacity (and speed), visiting policies and the financial implications of the additional costs of the pandemic and decreases in revenue.
- In the absence of standardised and robust national data on the sector, finding data about the impact of the pandemic on people who use and provide long-term care remains a challenge.
- The pandemic has laid bare long-standing problems in the long-term care system in England, such as the fragmentation of responsibilities, funding and workforce pressures, as well as the unequal relationship between the health and social care systems and the invisibility of groups such as working age adults with disabilities and unpaid carers in social care planning.

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1. Introduction

England experienced a severe initial wave of COVID-19¹ and now, in the second wave, the United Kingdom has been the first European country to record over 50,000 deaths of people who tested positive for COVID-19². Like in other countries, older people and people who live in residential and nursing care homes represented a large proportion of those who died. Also in common with many other countries, social care was initially not included in the COVID-19 pandemic planning and the social care sector entered the pandemic underfunded, understaffed and undervalued³. Analysis of the status of social care in the policy response by the Health Foundation showed that central government support for social care came too late. Initial policies targeted the social care sector in March. But the government's COVID-19: adult social care action plan was not published until 15 April – almost a month after countrywide social distancing measures had been introduced. In recognition of this belated response and the associated consequences, early in the second wave of COVID-19 in England, the Scientific Advisory Group (SAGE) that provide scientific advice to the government have emphasised the critical importance of reducing spread in care homes⁴.

This report provides an overview of the impact of COVID-19 so far on people who use and provide long-term care in England and of the policy and practice measures adopted to mitigate its impact. It focuses on England, as many of the policy areas relevant to long-term care and the response to the COVID-19 pandemic are devolved (and therefore different) in Northern Ireland, Scotland⁵ and Wales⁶, although some of the evidence included will be at United Kingdom level.

2. Extent of COVID-19 infections in the country and deaths

On 16 November 2020, and according to official estimates, there had been 1,192,402 cumulative cases of infections in England, 45,783 deaths (81.3 per 100,000) within 28 days of a positive test, and 53,102 deaths (94.3 per 100,000) where COVID-19 was mentioned in the death certificate⁷.

The first COVID-19 deaths were recorded in early March and, between then and end of June, mortality was above what would be expected compared to previous years. During July and the first part of August mortality was below the average from the previous 5 years, but increased substantially since the beginning of October (see figure 1). On the week of the 9th November, the 7-day average number of deaths was 305⁸.

¹ <https://www.health.org.uk/publications/report/adult-social-care-and-covid-19-assessing-the-impact-on-social-care-users-and-staff-in-england-so-far>

² <https://www.ecdc.europa.eu/en/cases-2019-ncov-eueea>

³ https://www.who.int/publications/i/item/WHO-2019-nCoV-Policy_Brief-Long-term_Care-2020.1

⁴ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/925853/S0768_Fifty-eighth_SAGE_meeting_on_Covid-19.pdf

⁵ A report on mortality linked to COVID-19 among people living in care homes in Scotland is available here:

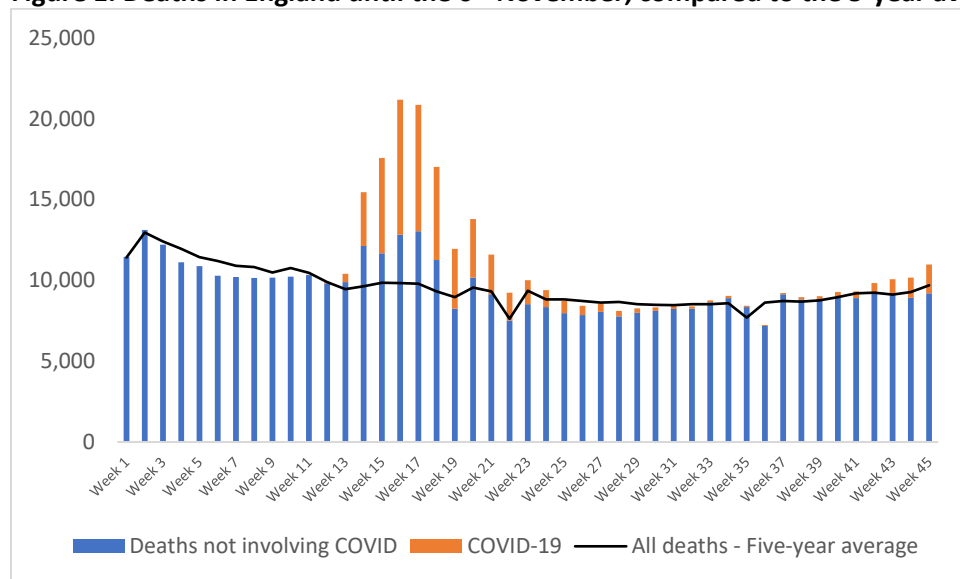
<https://ltccovid.org/2020/06/09/updated-report-deaths-in-scottish-care-homes-and-covid-19-up-to-3rd-june/>

⁶ A report on Wales is available here: <https://ltccovid.org/2020/06/13/the-covid-19-long-term-care-situation-in-wales/>

⁷ <https://coronavirus.data.gov.uk/about#england-covid-19-associated-deaths>

⁸ <https://coronavirus.data.gov.uk/details/deaths?areaType=nation&areaName=England>

Figure 1. Deaths in England until the 6th November, compared to the 5-year average.



Source: based on data from

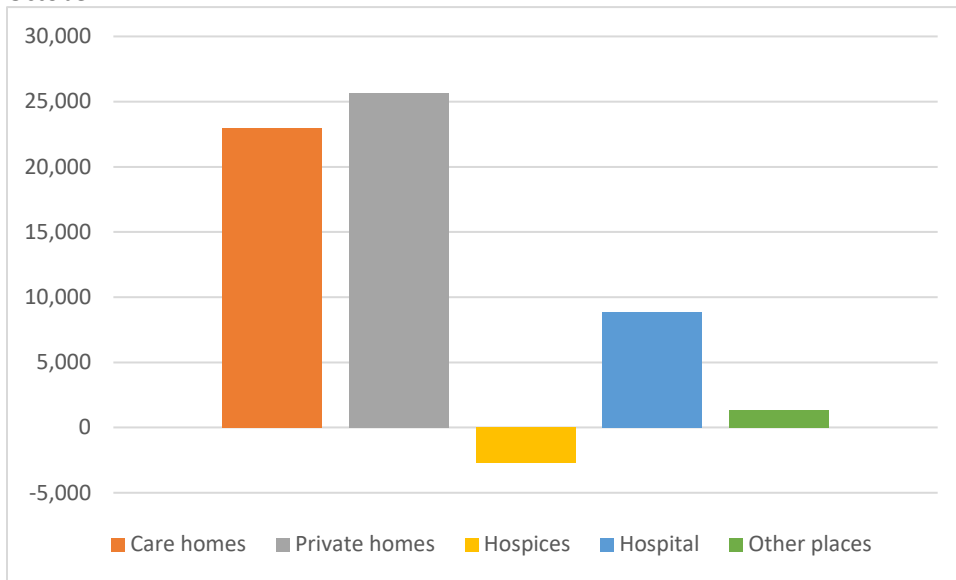
<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredweeklyinenglandandwalesprovisional/latest#glossary>

Public Health England has published estimates of excess deaths based on modelling of what would be expected given data from the previous five years. They estimate that, between the 20 March and 30 October, there had been 56,313 excess deaths in England, 1.19 times the number of expected deaths. Of these excess deaths, 53,701 (95.4%) would be accounted for by deaths where COVID-19 was mentioned in the death certificate⁹. Between 19 June and 7 August there were fewer deaths than expected.

The largest number of excess deaths between 20th March and 30th October happened in private homes (25,634, of which only 2,571, 10%, were registered as COVID-19), followed by deaths in care homes (22,948, of which 15,415, 60% were registered as COVID-19). In contrast, there were 2,724 fewer deaths than expected in hospices during that period (see figure 2).

⁹ <https://fingertips.phe.org.uk/static-reports/mortality-surveillance/excess-mortality-in-england-latest.html#deaths-by-underlying-cause>

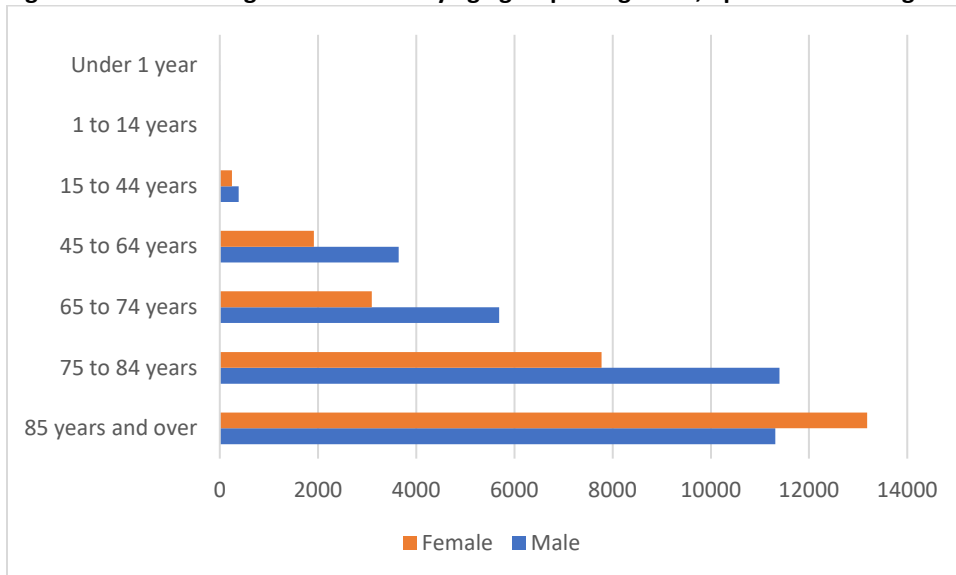
Figure 2. Excess deaths by place of death, estimated by Public Health England, between 20th March and 30th October



Source: <https://fingertips.phe.org.uk/static-reports/mortality-surveillance/excess-mortality-in-england-latest.html#place-of-death>

In common with other countries, COVID-19 deaths were predominantly among men and older people (figure 3).

Figure 3. COVID-19 registered deaths by age group and gender, up to week ending 6th November



Source: Based on data from the Office for National Statistics¹⁰

¹⁰

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredweeklyinenglandandwalesprovisional/weekending6november2020>

3. Population level measures to contain the spread of COVID-19

The UK government's response to COVID-19 in England has been described in detail in the Health Foundation's tracker of national policy and health system responses to COVID-19¹¹. The first two cases of COVID-19 in England were confirmed in the week beginning 27 January, 2020.¹² At the beginning of March there were 89 confirmed cases (and no deaths) in England¹³ and on 2 March the Prime Minister, Boris Johnson, chaired a meeting of Cobra, the Government's high level emergency planning committee. This resulted in a coronavirus 'action plan', published the next day, setting out a strategy consisting of four phases - *contain, delay, research* and *mitigate*.¹⁴ The initial *contain* phase involved detecting early cases and tracing contacts, together with advice to self-isolate for people returning from particular countries and general guidance on basic hygiene measures such as handwashing. However, by the 12 March the Government had decided that efforts to contain the disease were no longer feasible and announced it was moving to the next phase aiming to *delay* its spread. At the same time the risk level to the UK was officially raised from moderate to high.¹⁵

Around this time, scientific advice to the Government, based on the work of epidemiological modellers, was suggesting that the threat from the disease had been seriously under-estimated.¹⁶ On 16 March the Prime Minister announced stricter social distancing measures, urging people to stop non-essential contact with others, stop unnecessary travel (including to work) and shielding at home for the most vulnerable. The next day the Government launched a package of emergency economic support measures on a scale unknown in peacetime.¹⁷ Within a few days an instruction was issued to pubs, clubs, restaurants and other social venues to close and schools were to be closed from the 20 March (except for the children of key workers and vulnerable groups).¹⁸ A full lockdown was announced on 23 March, as the Prime Minister told the nation in a broadcast: 'I urge you at this moment of national emergency to stay at home'. People were allowed to leave their home only for very limited purposes such as essential shopping, medical need or when it was impossible to work from home.¹⁹

On 16 April the Government made it clear that the current measures were to remain in place for at least 3 further weeks and set out five tests that had to be met before any adjustment of these measures would be considered.²⁰ In his first statement following his own recovery from COVID-19, Boris Johnson summarised these tests as 'deaths falling; NHS protected; rate of infection down; really sorting out the challenges of testing and personal protective equipment (PPE); avoiding a second peak'.²¹ Indeed, the Government's handling of the 'challenges' of testing and PPE have attracted considerable critical comment and a legal challenge^{22,23}. On 10 May the Prime Minister outlined 'the first sketch of a road map for reopening society', which was published in full on 11 May as the Government's COVID-19

¹¹ <https://www.health.org.uk/news-and-comment/charts-and-infographics/covid-19-policy-tracker>

¹² [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(20\)30463-3/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)30463-3/fulltext)

¹³ <https://coronavirus.data.gov.uk/>

¹⁴ <https://www.gov.uk/government/publications/coronavirus-action-plan/coronavirus-action-plan-a-guide-to-what-you-can-expect-across-the-uk>

¹⁵ <https://www.gov.uk/government/news/covid-19-government-announces-moving-out-of-contain-phase-and-into-delay>

¹⁶ <https://www.iiss.org/blogs/survival-blog/2020/05/the-uk-and-covid-19>

¹⁷ <https://www.gov.uk/government/speeches/chancellor-of-the-exchequer-rishi-sunak-on-covid19-response>

¹⁸ <https://www.bbc.co.uk/news/uk-51952314>

¹⁹ <https://www.gov.uk/government/speeches/pm-address-to-the-nation-on-coronavirus-23-march-2020>

²⁰ <https://www.gov.uk/government/speeches/foreign-secretarys-statement-on-coronavirus-covid-19-16-april-2020>

²¹ <https://www.gov.uk/government/speeches/pm-statement-in-downing-street-27-april-2020>

²² <https://www.bmj.com/content/369/bmj.m1932>

²³ <https://goodlawproject.org/news/the-ppe-fiasco/>

‘recovery strategy’.²⁴ This document included the blunt statement that ‘The Government is particularly troubled by the impact of COVID-19 in care homes’.

Following announcements of some easing of restrictions in late May, the Prime Minister announced on the 10 June that the five tests were being met and a wide range of adjustments to the lockdown could now be made.²⁵ During June and July the lockdown measures were gradually relaxed²⁶, although there were local lockdowns in Leicester and there are a few areas with more restrictive measures and additional testing in place²⁷. People travelling from countries with high levels of COVID-19 infections were required to quarantine for two weeks on their return²⁸.

During August people were encouraged to eat out in restaurants and cafes through the “Eat out to Help out” scheme, through which the government subsidized meals in restaurants by 50%²⁹. From late August there was also a campaign to encourage people go back to their offices, as the high share of people working from home was considered detrimental to the businesses in the city centres³⁰.

This push to return to eating out, working from offices, and the re-opening of schools in early September was followed by a steady increase in cases of COVID-19, particularly in the North of England, where the drop in cases over lockdown had been less marked, and an increasing number of local restrictions were introduced, as well as some national level restrictions (only allowing gatherings of 6 people)³¹. On the 12th October the Prime Minister announced the introduction of a three-tier system of COVID-19 alert levels³². The implementation of the measures at local level were heavily contested, particularly by the Mayor of Manchester, due to concerns about insufficient economic packages available to the areas that with the highest levels of restrictions. A new national level lockdown started on the 5th of November³³ and is planned to last until 2nd December.

While the daily testing capacity in England has increased to reach just over 500,000 at UK level by early November³⁴, there are important problems with the capacity and organisation of the contact tracing system³⁵. In early November a mass asymptomatic testing pilot is underway in Liverpool, using rapid tests (including novel lateral flow rapid antigen tests)³⁶.

Following the announcement of the breakthrough with the BioNtech-Pfizer vaccine, plans are underway to prepare for mass immunization of vulnerable groups and healthcare workers through primary care settings³⁷. The joint committee on vaccination (JCVI) has recommended that older adults resident in

²⁴ <https://www.gov.uk/government/publications/our-plan-to-rebuild-the-uk-governments-covid-19-recovery-strategy/our-plan-to-rebuild-the-uk-governments-covid-19-recovery-strategy>

²⁵ <https://www.gov.uk/government/speeches/pm-statement-at-the-coronavirus-press-conference-10-june-2020>

²⁶ <https://www.gov.uk/government/publications/coronavirus-outbreak-faqs-what-you-can-and-cant-do/coronavirus-outbreak-faqs-what-you-can-and-cant-do>

²⁷ <https://www.bbc.co.uk/news/uk-england-leicestershire-53283967>

²⁸ <https://www.gov.uk/guidance/travel-advice-novel-coronavirus>

²⁹ <https://www.gov.uk/guidance/get-a-discount-with-the-eat-out-to-help-out-scheme>

³⁰ See for example <https://www.bbc.co.uk/news/uk-53942542>

³¹ <https://www.gov.uk/government/speeches/pm-press-conference-statement-9-september-2020>

³² <https://www.gov.uk/government/speeches/pm-commons-statement-on-coronavirus-12-october-2020>

³³ <https://www.gov.uk/guidance/new-national-restrictions-from-5-november>

³⁴³⁴ <https://coronavirus.data.gov.uk/details/testing>

³⁵ <https://blogs.bmj.com/bmj/2020/09/18/chris-ham-the-time-has-come-to-give-local-leaders-control-of-covid-19-test-and-trace/>

³⁶ <https://www.gov.uk/government/news/liverpool-to-be-regularly-tested-for-coronavirus-in-first-whole-city-testing-pilot>

³⁷ <https://www.bma.org.uk/advice-and-support/covid-19/gp-practices/covid-19-vaccination-programme>

care homes, and care home workers should be the first group prioritised to receive the vaccine once available³⁸.

4. Impact of the COVID-pandemic on people who use and provide long-term care in England

4.1. Rates of infection and mortality among people who use long-term care and staff

A detailed report on the impact of COVID-19 on social care users and staff in England was published by the Health Foundation³⁹ in July 2020. The report highlights the lack of data systems in place for social care and the difficulty this has created to track the impact of the pandemic, particularly for people relying on domiciliary care.

4.1.1. Rates of infection and mortality in care homes

In England there are an estimated 15,481 care homes with 457,428 beds and, of these, 10,894 are care homes for older people (with 411,272 beds)⁴⁰. During the first wave of the pandemic, the Vivaldi study⁴¹, which covered 9,081 care homes in England that provide care for older people or for people living with dementia, found that 56% of care homes reported at least one confirmed case of COVID-19 and estimated that 20% of residents in those care homes and 7% of staff tested positive. The study also found that care homes with higher levels of infections among resident and staff reported more frequent use of bank or agency staff. There were lower levels of infections in residents in care homes where staff receive sick pay. There were regional differences, but those could be in part due to differences in testing regimes.

On the other hand, Public Health England's data on outbreaks (available until the week starting 13 July), shows that there had been 6,811 outbreaks in care homes (44% of the 15,476 care homes in England). There were important variations in the timing and the relative number of outbreaks in different parts of England. The share of care homes with outbreaks ranged from 30% in the South West to 55% in the North West (figure 4).

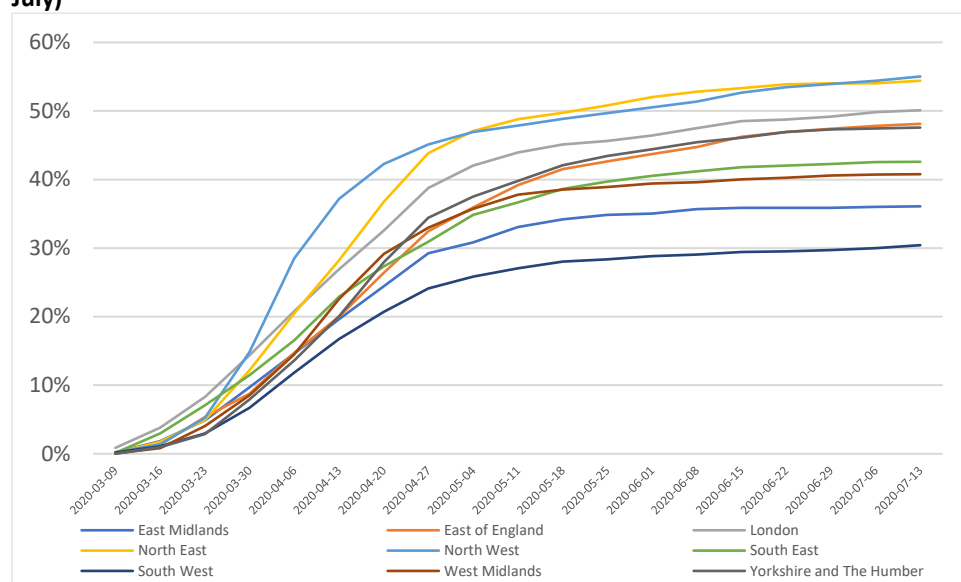
³⁸ <https://www.gov.uk/government/publications/priority-groups-for-coronavirus-covid-19-vaccination-advice-from-the-jcvi-25-september-2020>

³⁹ <https://www.health.org.uk/publications/reports/adult-social-care-and-covid-19-assessing-the-impact-on-social-care-users-and-staff-in-england-so-far>

⁴⁰ Bell D, Comas-Herrera A, Henderson D, Jones S, Lemmon E, Moro M, Murphy S, O'Reilly D and Patrignani P (2020) COVID-19 mortality and long term care: a UK comparison. Article in LTCcovid.org, International Long-Term Care Policy Network, CPEC-LSE, August 2020. <https://lccovid.org/2020/08/28/covid-19-mortality-and-long-term-care-a-uk-comparison/>

⁴¹ <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/impactofcoronavirusincarehomesinenglandvivaldi/26mayto19june2020>

Figure 4. Cumulative percentage of care homes with COVID-19 outbreaks by region (data up to week starting 13 July)



Source: Public Health England, 23 July 2020⁴²

Obtaining estimates of the numbers of deaths of care home residents linked to the COVID-19 pandemic is not straightforward.

Data on the number of COVID-related deaths in care homes (that is, care homes as the place of death) is regularly published by the Office of National Statistics and are available for the whole period of the pandemic. Between the 28 December and the 6th November, an estimated 15,659 people would have died linked to COVID-19 in care homes⁴³. However, this figure does not include care home residents who died in other places (including hospital). The most recent Office for National Statistics estimate of the total number of deaths of care home residents shows that, between the 28 December and the 12 June, there had been 89,018 deaths of care home residents in England, 28,018 more than during the same period in 2019. Of these “excess deaths”, 18,562 (65.8%) were registered as COVID-19⁴⁴. Since the 12th June and until the 13th November, another 3,084 deaths of care home residents have been notified to the Care Quality Commission as being linked to COVID-19, 2,191 of these deaths happened in a care home and 847 (24%) in hospital⁴⁵ this would bring the number of deaths of care home residents linked to COVID-19 to 20,799 (representing 4.54% of all care home beds in England).

⁴² <https://www.gov.uk/government/statistical-data-sets/covid-19-number-of-outbreaks-in-care-homes-management-information>

⁴³

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/weeklyprovisionalfiguresondeathsregisteredinenglandandwales>

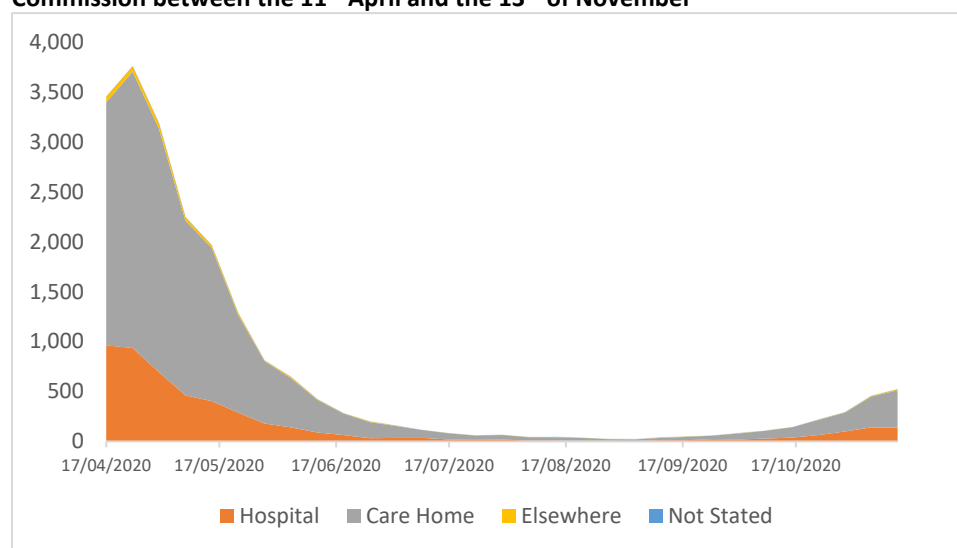
⁴⁴

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglandandwales/latest>, based on data for figure 2.

⁴⁵

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/numberofdeathsincareshomesnotifiedtothecarequalitycommissionengland>

Figure 5: Weekly number of deaths of care home residents attributed to COVID-19 notified to the Care Quality Commission between the 11th April and the 13th of November



Source:

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/numberofdeathsincarehomesnotifiedtothecarequalitycommissionengland>

During the period from 20th March and 30th October, and according to estimates by Public Health England⁴⁶, there were 22,948 excess deaths in care homes (compared to the previous 5 years). Of these, 15,415 (60%) were registered as COVID-19, the number of excess deaths in this period would amount to 5% of all care home beds. These figures do not include all deaths of care home residents, as some will have died in hospital.

4.1.2. COVID-related deaths among people who use community-based care services

There is relatively little data on the impact of COVID-19 on people who use long-term care and live in private households. Using data from the Care Quality Commission (CQC) the Health Foundation estimated that, between the 23rd March and the 19th of June 2020, there were an additional 4,500 deaths among people using domiciliary care from providers registered with the CQC, compared to the previous three years during the same period (an increase of 225%)⁴⁷. The deaths of 819 service users had been notified as involving COVID-19⁴⁸ during this period.

It is important to note that these data would not include people relying on care that is entirely provided by family and other unpaid carers or by paid carers that are not registered with the CQC. As noted in section 3, figure 2, since the beginning of the pandemic there have been 25,634 excess deaths in private households, of which only 10% were attributed to COVID-19⁴⁹.

⁴⁶ <https://fingertips.phe.org.uk/static-reports/mortality-surveillance/excess-mortality-in-england-latest.html#introduction>

⁴⁷ <https://reader.health.org.uk/adult-social-care-and-covid-19-assessing-the-impact-on-social-care-users-and-staff-in-england-so-far/part-1-how-did-covid-19-s-impact-on-social-care-unfold#the-total-mortality-among-those-receiving-social-care-in-their-homes>

⁴⁸

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvedwithcovid19inthecaresectorenglandandwales/deathsoccurringupto12june2020andregisteredupto20june2020provisional#deaths-of-recipients-of-domiciliary-care-in-england>

⁴⁹ <https://fingertips.phe.org.uk/static-reports/mortality-surveillance/excess-mortality-in-england-latest.html#introduction>

4.1.3. COVID-19 related deaths among people with intellectual disabilities

There are three sources of information on the deaths of people with intellectual disabilities in England. The LeDeR programme, a national voluntary programme for the notification and review of all deaths of people with learning disabilities in England⁵⁰, reports weekly notifications of deaths confirmed or suspected as caused by COVID-19 and deaths from any other cause⁵¹. To 6th November 2020, in total 750 confirmed/suspected COVID-19 deaths of people with intellectual disabilities have been notified to the LeDeR programme, with a first peak of deaths in April which, taking into account rates of under-identification in notifications to the LeDeR programme⁵², leads to an estimation of 1,154 COVID-19 deaths among people with learning disabilities in England to date. Notified deaths from non-COVID-19 causes (1,855 notified deaths; 2,854 estimated deaths; in 2020 to 6th November) were also higher during April. It should be noted that pre-COVID-19, avoidable mortality rates were twice as high for people with intellectual disabilities⁵³, indicating a high number of ‘excess’ deaths pre-dating COVID-19. In the first peak of the pandemic, COVID-19 death rates for adults with learning disabilities were 3.6 times higher than for the general population, rising to 6.3 times when controlling for age and sex⁵⁴.

COVID-19 death rates for adults with learning disabilities were higher than those of the general population at all ages, with the peak age of death for people with learning disabilities being 55-64 years⁵⁵. Within the population of people with learning disabilities, COVID-19 death rates were higher amongst men, and amongst Asian/Asian British and Black/Black British communities⁵⁶. Unlike in the general population, 82% of COVID-19 deaths of people with learning disabilities happened in hospital.⁵⁷

⁵⁰ http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL.pdf

⁵¹ <https://www.england.nhs.uk/publication/covid-19-deaths-of-patients-with-a-learning-disability-notified-to-leder/>

⁵² <https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities>

⁵³ http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL.pdf

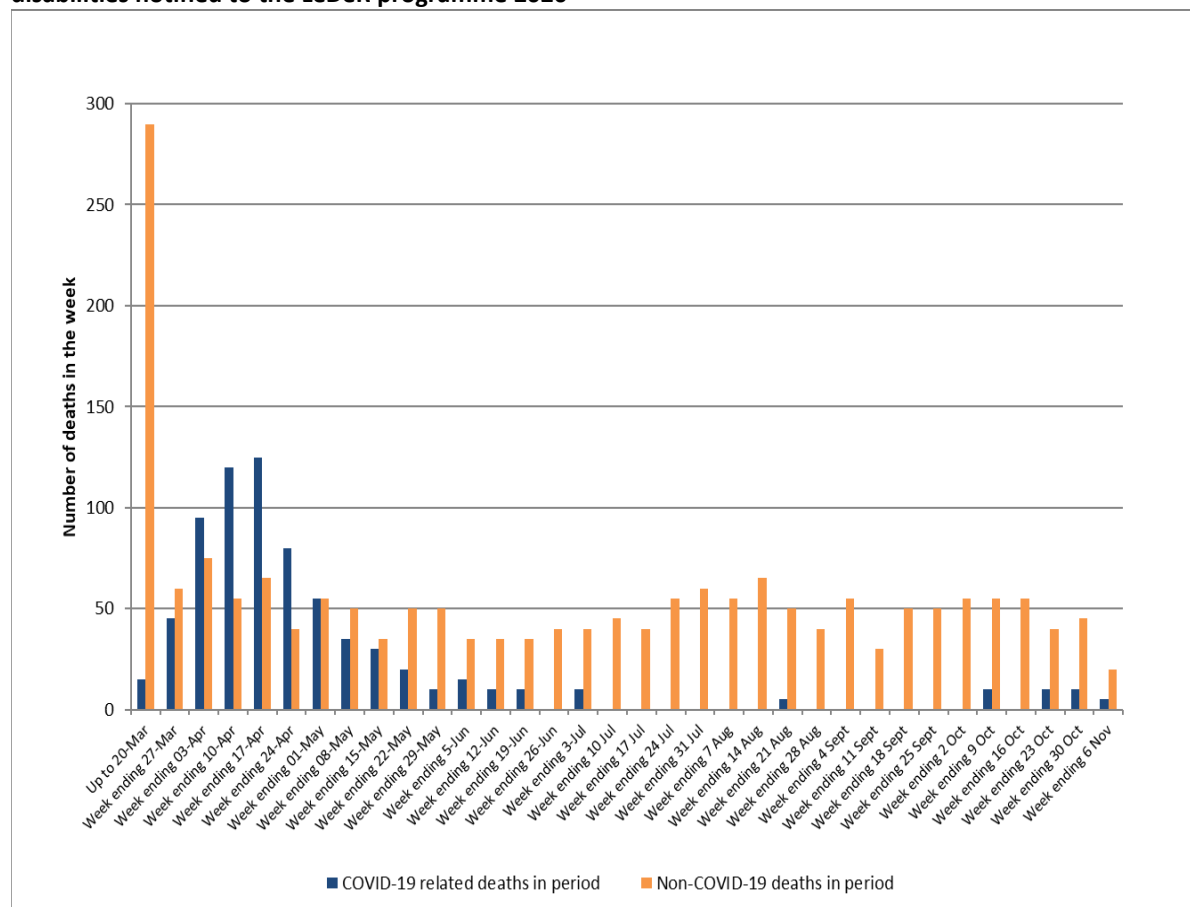
⁵⁴ <https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities>

⁵⁵ <https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities>

⁵⁶ <https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities>

⁵⁷ <https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities>

Figure 6. Confirmed/suspected COVID-19 deaths and deaths from all other causes of people with intellectual disabilities notified to the LeDeR programme 2020



Source: based on data from the LeDeR programme published by NHS England⁵⁸

NHS England also report weekly data on confirmed COVID-19 deaths in hospital of people flagged in hospitals as people with intellectual disabilities or autistic people⁵⁹. Flagging began on 24th March 2020, and to 11th November 2020 has reported 586 COVID-19 deaths (taking into account under-ascertainment an estimated 781 deaths). From 24th March to 11th November, 2.1% of all confirmed COVID-19 deaths in hospitals where flagging information was available were people with intellectual disabilities.

Finally, the Care Quality Commission published a one-off analysis⁶⁰ of 386 death notifications of adults with intellectual disabilities using community-based social care or living in residential care from 10th April to 15th May 2020, compared to 165 death notifications for the same time period in 2019. Of the 386 deaths in 2020, 206 were confirmed/suspected COVID-19 deaths and 180 were deaths notified as not COVID-19 related. The age profile of COVID-19 related deaths for people with intellectual disabilities was younger than the general population: 22% of deaths age 25-54 years; 33% of deaths age 55-64 years; 26% of deaths age 65-74 years; 19% of deaths age 75+ years.

⁵⁸ <https://www.england.nhs.uk/publication/covid-19-deaths-of-patients-with-a-learning-disability-notified-to-leder/>

⁵⁹ <https://www.england.nhs.uk/statistics/statistical-work-areas/covid-19-daily-deaths/>

⁶⁰ <https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-people-learning-disability>

An analysis of reviews of 163 people with learning disabilities who died with COVID-19 reported that 35% of people with learning disabilities were living in residential care, a further 19% were living in nursing care, 25% were living in supported living accommodation and 18% were living on their own or with their family.⁶¹ ‘Frailty’ or ‘learning disabilities’ were found as rationales for “Do not attempt cardiopulmonary resuscitation” (DNACPRs) for people who had died of COVID-19, but not in DNACPRs for a matched group of 43 people with learning disabilities who died of other causes in the same time period.⁶²

4.1.4. COVID-19 infections and deaths among people living with dementia

Data published by the Office of National statistics has shown that 25.6% of all **COVID-19 related deaths** between March and June 2020 in England and Wales corresponded to people living with dementia, and dementia was also the most common pre-existing condition found among deaths involving COVID-19⁶³. There was an increase of 52.2% (5,404) **excess deaths** due to dementia⁶⁴ between the same time period (March – June). These excess deaths may be explained by both missed COVID-19 diagnosis and COVID indirect deaths. Covid-19 indirect deaths may be as results of, for instance lack of appropriate care due to shortage in care home staff, difficulties to access medical care during the hardest weeks of the pandemic and the deleterious effect of confinement and isolation. Between 7th March and 1st May 2020, the largest increases in **non-Covid-19 deaths** compared to the five years average in England and Wales were due to dementia and dementia was the largest common cause of death for the non-Covid-19 deaths⁶⁵. Deaths from dementia in England in September 2020 have returned to the five-year average for the same month⁶⁶.

Deaths in the community

The number of **deaths in private homes** from dementia increased by 79% in England between 14th March and 11th September compared the five-year average⁶⁷.

Deaths in care homes

⁶¹ <http://www.bristol.ac.uk/sps/leder/news/2020/leder-covid-19-reviews.html>

⁶² <http://www.bristol.ac.uk/sps/leder/news/2020/leder-covid-19-reviews.html>

⁶³

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsinvolvedwithcovid19englandandwales/deathsoccurringinjune2020#pre-existing-conditions-of-people-who-died-with-covid-19>

⁶⁴

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/analysisofdeathregistrationsnotinvolvingcoronaviruscovid19englandandwales28december2019to1may2020/technicalannex#deaths-due-to-dementia-and-alzheimer-disease>

⁶⁵

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/coronaviruscovid19roundup1to5june2020/2020-06-05>

⁶⁶

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/monthlymortalityanalysisenglandandwales/september2020>

⁶⁷

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinprivatehomesenglandandwalesprovisional/deathsregisteredfrom28december2019to11september2020#deaths-in-private-homes-by-cause-of-death>

Half (49.5%) of all COVID-19 related deaths in **care homes** in England and Wales between March and June were in people living with dementia⁶⁸. COVID-19 deaths may have been deathlier partly due to the barriers to access healthcare, including primary care and hospital admission, compromised during the early days of the pandemic for people in care homes (where around 86% of residents have dementia)⁶⁹.

4.1.5. COVID-19 infections and deaths among people working in social care

People working in face to face roles in social care have been at higher risk of contracting COVID-19 infections and of dying than people working in other jobs. A survey that tested 36,061 people who were not resident in care homes or other institutions between the 26th April and the 27th June found that, among people working in health and social care roles that involved facing patients or care home residents, 1.58% tested positive for SARS-CoV-2, compared to 0.27% of people with other jobs⁷⁰.

An analysis, also by the Office of National Statistics, of the rates of COVID-related deaths of different professions found that, between the 9th of March and 25th of May 2020 there had been 268 deaths involving COVID-19 among social care workers. The age-standardized rates of deaths for social care workers were significantly higher than for the whole population aged 20 to 64: 50.1 deaths per 100,000 men (compared to 19.1) and 19.1 deaths per 100,000 women (compared to 9.7)⁷¹. By 20th July 2020, the total number of deaths among social care workers involving covid-19 had increased to 312⁷².

4.2. Other impacts

There is also growing evidence of other impacts of the pandemic in the wellbeing and physical and mental health of people who provide and use long-term care. A survey of the Association of Directors of Social Services (ADASS) has found that there is an increase in the numbers of people approaching social services and of unmet need⁷³.

4.2.1. People living in care homes

There is concern and, increasingly, international evidence that some of the measures taken to reduce the risk of COVID-19 infections in care homes, such as closing care homes to visitors (including family members), reduction in social interactions and activities and needing to isolate, have had negative

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https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvedwithcovid19inthecaresectorenglandandwales/deathsoccurringupto12june2020andregisteredupto20june2020provisional?WT.mc_id=f5e0eb1233c5d2a1a4a1b591e46fecbd&hootPostID=1376c0e546f27d0e33d8ce1e242a810f

69 <https://ltccovid.org/2020/06/01/updated-report-the-impact-of-the-covid-19-pandemic-on-people-living-with-dementia-in-uk/>

70

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/coronaviruscovid19infectionsinthecommunityinengland/july2020#infection-rates-among-workers-over-the-study-period>

71

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/coronaviruscovid19relateddeathsbyoccupationenglandandwales/deathsregisteredbetween9marchand25may2020#overview-of-coronavirus-related-deaths-by-occupation>

72

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/adhocs/12112deathsinvolvedwithcovid19amonghealthandsocialcareworkersinenglandandwalesdeathsregisteredbetween9marchand20july2020>

73 <https://www.adass.org.uk/media/7967/adass-coronavirus-survey-report-2020-no-embargo.pdf>

impacts on the wellbeing and mental health of people living in care homes⁷⁴. In a survey of care homes from across England found that by late May and early June, 85% of managers had detected low mood among residents⁷⁵.

Guidance issued by the government on 2 April said that care homes should advise family and friends not to visit except in exceptional circumstances⁷⁶ the survey above found that more than half closed to visitors before restrictions were imposed. As the first wave of infections grew and the impact on mortality among care home residents became increasingly clear, care homes strictly enforced restrictions on visits. As the second wave of infections grips the country, there is growing concern about the impact of the restricted visits policy on care home residents with families reporting a decrease in wellbeing and a detrimental impact on mental and physical health⁷⁷. An assessment by SAGE noted that the prohibition of visits would likely have a low impact on transmission but “substantial social and emotional impact on residents and, for end of life patients in particular, relatives”⁷⁸.

4.2.2. People living in the community who use long-term care

There is emerging evidence that reduced use of social support services has had detrimental effects on the quality of life of people affected by dementia and older adults^{79,80}.

4.2.3. People who are employed to work in social care

A survey⁸¹ of 296 frontline care workers that took place during July and August found that 81% indicated increased workload since the onset of COVID-19 and 56% of increased their working hours. 18% had to self-isolate, but nearly a fifth of those who needed to self-isolate did not receive any pay. The survey also found that 22% of care workers thought they had not received adequate COVID-19 training or clear guidance, and 16% had not had the necessary PPE to do their job safely.

Nearly half of the respondents (47%) indicated their general-health had worsened since the onset of COVID-19 and 60% indicated that the amount of time their jobs made them feel depressed, gloomy or miserable had increased since COVID-19. Also, 81% reported an increase in the amount of time that their jobs made them feel tense, uneasy or worried. A significant minority of 23% indicated their job

⁷⁴ <https://itccovid.org/2020/11/01/pre-print-rapid-review-of-the-evidence-on-impacts-of-visiting-policies-in-care-homes-during-the-covid-19-pandemic/>

⁷⁵ Rajan, S., Comas-Herrera, A. and Mckee, M., 2020. Did the UK Government Really Throw a Protective Ring Around Care Homes in the COVID-19 Pandemic?. *Journal of Long-Term Care*, (2020), pp.185–195. DOI: <http://doi.org/10.31389/jltc.53>

⁷⁶

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/880274/Admission_and_Care_of_Residents_during_COVID-19_Incident_in_a_Care_Home.pdf

⁷⁷ <https://www.theguardian.com/world/2020/sep/23/covid-ban-on-care-home-visitors-risks-premature-deaths-experts-warn>

⁷⁸

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/925856/S0770_NPIs_table_pivot.pdf

⁷⁹ Giebel, C., Cannon, J., Hanna, K., et al. (2020) Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: a qualitative study, *Aging & Mental Health*,

<https://www.tandfonline.com/doi/full/10.1080/13607863.2020.1822292>

⁸⁰ Giebel, C., Lord, K., Cooper, C., et al. (2020), A UK survey of COVID-19 related social support closures and their effects on older people, people with dementia, and carers. *Int J Geriatr Psychiatry*. <https://doi.org/10.1002/gps.5434>

⁸¹ https://www.pssru.ac.uk/blog/the-impact-of-covid-19-on-social-care-workers-workload/?utm_source=rss&utm_medium=rss&utm_campaign=the-impact-of-covid-19-on-social-care-workers-workload

satisfaction had increased, whereas 42% said that they had become a little or a lot less satisfied with their job since COVID-19.

In another survey of 43 care home managers in England, staff had needed to isolate in 72% of care homes, 10% reporting staff hospitalisations and 3% reporting a death. 43% of managers reported staffing shortages with 1 in 3 having to use agency staff, who accounted for between 2 and 37% of their workforce. Providers generally reported receiving little support with surge staffing, while 75% of managers also reported that they were concerned for the morale, mental health and wellbeing of their staff⁸².

In addition, data from Skills for Care indicates that the percentage of days lost to staff sickness have increased by 180% (from 2.7% before the pandemic, to 7.5% between March and August 2020)⁸³. Despite this, the vacancy rate among providers decreased from 8.6% in February 2020 to 7% in August 2020⁸⁴.

4.2.4. Unpaid or informal carers

Evidence suggests that, since the beginning of the COVID-19 pandemic, a substantial number of people have taken on new care responsibilities.

A Carers week and an Office for National Statistics report show that the number of people providing unpaid care has increased substantially since the COVID-19 related lockdown measures were put in place in March 2020. The ONS report states that 48% of people in the UK cared for someone outside their own household in April 2020⁸⁵. The Carers week report estimates that 4.5 million people in the UK have become unpaid carers during the COVID-19 outbreak in the UK⁸⁶.

The reports also show that people who have taken on new care responsibilities continue to be more likely to be female, although there was also a high proportion of men taking on new care responsibilities. Carers who have taken on care responsibilities since the onset of the COVID-19 pandemic were slightly younger (45-54 years) compared to the groups that are usually more like to provide care (aged 55-64)⁸⁷. The most frequently reported reasons for an increase in care responsibility were increased care needs and reduction or suspension of local services. The Carers week report found that new carers were also more likely to be working and to have children (under 18 years).⁸⁸

The amount care provided by family carers has increased

⁸² Rajan, S., Comas-Herrera, A. and Mckee, M., 2020. Did the UK Government Really Throw a Protective Ring Around Care Homes in the COVID-19 Pandemic?. *Journal of Long-Term Care*, (2020), pp.185–195. DOI: <http://doi.org/10.31389/jltc.53>

⁸³ <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/Topics/COVID-19/days-lost-due-to-sickness.aspx>

⁸⁴ <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/Topics/COVID-19/Recruitment-and-retention.aspx>

⁸⁵

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/morepeoplehavebeenhelptoothersoutsidetheirhouseholdthroughthecoronaviruscovid19lockdown/2020-07-09>

⁸⁶ https://www.carersuk.org/images/CarersWeek2020/CW_2020_Research_Report_WEB.pdf

⁸⁷

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/morepeoplehavebeenhelptoothersoutsidetheirhouseholdthroughthecoronaviruscovid19lockdown/2020-07-09>

⁸⁸ https://www.carersuk.org/images/CarersWeek2020/CW_2020_Research_Report_WEB.pdf

Carers UK have reported that care responsibilities have increased for most carers, with the average time spent caring increasing by 10 hours to 65 hours of unpaid care per week. A small proportion of carers, however, have provided less care.⁸⁹ An increase in care responsibility and time spent caring was also reported among most unpaid carers of people with dementia (73%)⁹⁰. Many carers attributed the increase in time spent caring to reduced availability of services. This proportion was particularly high among Black, Asian and Minority Ethnic (BAME) carers⁹¹.

Carers express concerns

The survey by Carers UK showed that a large proportion of unpaid carers are concerned about what would happen to the care recipient if the unpaid carer became unable to provide care (87%). A second concern expressed was the risk of infection due to domiciliary carers entering people's homes. Carers of people with dementia also reported that people with dementia had difficulty following the distancing rules and to understand why their routines (e.g. support groups, day care) had been disrupted⁹².

Carers experience an impact on their mental health, finances and well-being

Carers have also reported delays of health treatment for the person they care for (57%) and for themselves (38%)⁹³. Reduced access to health care and social services for the person they support was also reported by carers of people with dementia (90% of 795 respondents)⁹⁴. More than half of carers (65%) in the Carers UK survey have reported to have postponed attending health care services for their own health needs⁹⁵.

There is also evidence of a negative impact on carers finances, with some incurring increased costs (food, bills, equipment) and reduced ability to work or loss of employment^{96,97}. While some carers highlighted that working remotely provided them with greater flexibility to manage care and work, others experienced greater challenges. Research on unpaid carers caring for someone outside their household found that carers with paid jobs worked fewer hours than other people in employment, and that female carers working fewer hours than male carers. Financial pressure on carers was also illustrated through the use of foodbanks. 106,450 carers (1.76% of carers) reported that their household had to rely on foodbanks in the past month. Foodbank use was higher among female and among young carers (aged 17-30). The research also showed that in the households of 228,625 unpaid carers someone had gone hungry in the week prior to the survey. Again, this was higher among females and young carers (aged 17-30)⁹⁸.

⁸⁹

https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf

⁹⁰ <https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf>

⁹¹

https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_Oct20.pdf

⁹² <https://www.tandfonline.com/doi/full/10.1080/13607863.2020.1822292>

⁹³

https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_Oct20.pdf

⁹⁴ <https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf>

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https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_Oct20.pdf

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https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf

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https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_Oct20.pdf

⁹⁸ http://circle.group.shef.ac.uk/wp-content/uploads/2020/06/Caring-and-COVID-19_Hunger-and-mental-wellbeing-2.pdf

Many carers have expressed the experience of stress and a negative impact on their physical and mental health^{99,100,101,102,103}. Carers UK found that the negative impact on carers mental health was greater among carers experiencing financial difficulties¹⁰⁴. Research by Giebel and colleagues found that variation in hours of support associated with higher levels of anxiety and lower levels of well-being¹⁰⁵.

4.2.5. People with intellectual disabilities and autistic people

Relatively little systematic information is available concerning the impact of COVID-19 on the lives of people with intellectual disabilities and autistic people in England, although there is a consistent picture from blogs run by self-advocacy and other organisations in England^{106,107} and surveys of people with intellectual disabilities in Scotland^{108,109} and Wales^{110,111}. The most common concerns raised include the following, although there appear to be large variations in how local authorities have operated:

- the reduction or removal of social care support, such as support workers, social workers, day services and personal assistants
- increased social isolation and worries about mental health
- exclusion from digital forms of communication and keeping in contact, although for some people this has improved considerably as the pandemic continues
- anxiety and confusion about ambiguous and changing lockdown rules and guidance, including inconsistencies in eligibility for shielding
- difficulty in accessing daily essentials such as food and medicines
- anxiety about the health consequences of contracting COVID-19 for themselves and those close to them, including family members and paid support workers
- accessing non-COVID-19 health care, such as primary care and annual learning disability health checks
- a lack of clarity about the future of people's jobs
- worries about the future.

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<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/morepeoplehavebeenhelptoothersoutsidetheirhouseholdthroughthecoronaviruscovid19lockdown/2020-07-09>

¹⁰⁰ https://www.carersuk.org/images/CarersWeek2020/CW_2020_Research_Report_WEB.pdf

¹⁰¹ <https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf>

¹⁰²

https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_Oct20.pdf

¹⁰³ <https://onlinelibrary.wiley.com/doi/10.1111/jar.12811>

¹⁰⁴

https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_Oct20.pdf

¹⁰⁵ <https://onlinelibrary.wiley.com/doi/10.1002/gps.5434>

¹⁰⁶ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/925820/covid-and-people-with-learning-disabilities-or-autism-easy-read_v2b.pdf

¹⁰⁷ <https://www.learningdisabilityengland.org.uk/what-we-do/keeping-informed-and-in-touch-during-coronavirus/connecting-people-including-webinars/>

¹⁰⁸ <https://inclusionscotland.org/wp-content/uploads/2020/04/Initial-Findings-Report-.pdf>

¹⁰⁹ <https://www.sclcd.org.uk/wp-content/uploads/2020/06/SCLD-Coronavirus-Report-FINAL.pdf>

¹¹⁰ <https://allwalespeople1st.co.uk/wp-content/uploads/2020/05/The-Effect-of-the-Coronavirus-Pandemic-on-People-with-Learning-Disabilities-Across-WalesPhaseOneFinalDraft.pdf>

¹¹¹ <https://allwalespeople1st.co.uk/wp-content/uploads/2020/08/AMBER-The-Effect-of-the-Coronavirus-Pandemic-on-People-with-Learning-Disabilities-Across-Wales.pdf>

4.2.6. People living with dementia

Infection control measures to contain the spread of infection in care homes have involved a ban on external visitors (including close family and partners in care) and additional isolation measures such as asking residents to stay in their rooms. This means that many people with dementia have not been able to see their families for months and some who did, may have seen these visits extremely reduced in terms of frequency and duration as a result of protective measures. There are multiple reports warning about the alarming rate of deterioration that people with dementia are experiencing under these isolating conditions and being detached from their families. For instance, a survey conducted by the charity Alzheimer's Society found that 79% of care homes surveyed reported that the lack of social contact is causing a deterioration in the health and wellbeing of their residents with dementia¹¹². In an unprecedented joint effort, the leading dementia charities in England are currently campaigning for family and friend carers to be granted the status of key workers^{113,114}, which would allow them the same access to care homes than care home members of staff.

Support in the community

Social support services closed down during the pandemic in the UK, which has contributed to worse quality of life and anxiety in people with dementia^{115,116}. Moreover, many informal carers decided to discontinue paid carers entering the home due to fear of infection, which resulted in extra workload for family caregivers¹¹⁷.

Increase in anti-psychotic prescribing

Analysis of NHS data has shown an increase in anti-psychotic prescribing to people with dementia during the Covid-19 pandemic¹¹⁸. Despite their use having been reduced over time prior to the pandemic (due to concerns about their safety and efficacy) antipsychotics are thought to be used as a resort during the pandemic in response to worsened agitation and psychosis secondary to Covid-19 restrictions in care homes.

5. Brief background to the long-term care system

There is widespread and long-standing consensus that the social care system in England is not fit for purpose and is in need of reform.¹¹⁹ Successive governments have made promises to reform the system but no substantial action has been taken. Boris Johnson, on becoming Prime Minister in July 2019, stated: 'We will fix the crisis in social care once and for all with a clear plan we have prepared to give every older person the dignity and security they deserve'.¹²⁰ There were signs that social care funding reform is receiving more attention within government as of July 2020¹²¹. However, at the time of writing (November 2020), the government has not tabled any firm proposals. In the meantime, the Health and

¹¹² <https://www.alzheimers.org.uk/news/2020-06-05/thousands-people-dementia-dying-or-deteriorating-not-just-coronavirus-isolation>

¹¹³ <https://www.alzheimers.org.uk/news/2020-07-09/open-letter-secretary-state>

¹¹⁴ https://www.theguardian.com/commentisfree/2020/jul/19/please-matt-hancock-let-us-see-our-loved-ones-with-dementia?CMP=share_btn_tw

¹¹⁵ <https://pubmed.ncbi.nlm.nih.gov/32946619/>

¹¹⁶ <https://pubmed.ncbi.nlm.nih.gov/32954794/>

¹¹⁷ <https://pubmed.ncbi.nlm.nih.gov/32900360/>

¹¹⁸ <https://www.thelancet.com/journals/lanour/article/PIIS1474-4422%2820%2930370-7/fulltext>

¹¹⁹ <https://www.health.org.uk/sites/default/files/NHS-70-What-Can-We-Do-About-Social-Care.pdf>

¹²⁰ <https://www.homecareinsight.co.uk/pm-pledges-to-fix-social-crisis-once-and-for-all-matt-hancock-retains-post/>

¹²¹ <https://www.theguardian.com/society/2020/jul/27/camilla-cavendish-the-woman-charged-with-shaking-up-social-care>

Social Care Committee has become the latest in a long line of Parliamentary Select Committees to undertake an inquiry into the social care system – this time on funding and workforce. That committee, like those that have gone before, call for urgent reform to the system¹²².

5.1. Governance

The Department of Health and Social Care has overall policy responsibility for adult long-term care policy in England. The assessment of care needs, and the commissioning and organisation of care is the responsibility of 152 local authorities, a small minority of which also run and deliver some care services. Government financial support for local authorities, including their social care responsibilities, is channelled through the Ministry of Housing, Communities and Local Government. The Care Quality Commission (CQC) is an executive non-departmental public body of the Department of Health and Social Care and serves as the independent regulator for both health and long-term care. Although there are initiatives at local and regional levels which aim to integrate health and long-term care services (with varying degrees of success), they remain two separate systems.

5.2. Financing

Local authorities are funded largely through a combination of a grant from central government and local revenue-raising mechanisms, including council tax for example. Social care funding is not ring-fenced, which means that local authorities can decide how much of their budget they allocate to care. Unlike the NHS, where healthcare is free to those using it, access to social care is determined by both need and means. A restrictive means test, which has not been adjusted since 2010, means that people with property (including housing), savings or income in excess of £23,250 must meet the entirety of their care costs alone. Those with means below the threshold of £23,250 may be eligible for part or full state funding for their care but they must also be deemed to have sufficiently severe care needs.

The distinction between ‘health’ and ‘care’ creates further inequity. A person deemed to have health needs may be able to access social care via the NHS’s continuing healthcare programme (although subject to restrictive eligibility criteria and long waiting times), but someone with personal care needs (e.g. arising from dementia) and no medical requirements is subject to the means test.¹²³

In 2018/19, total expenditure on social care by councils amounted to £22.2 billion. There are few estimates of private spending on care, however the National Audit Office has estimated the size of the self-funder market (i.e. those who pay for their care) at £10.9 billion in 2016/17.¹²⁴

During the last decade, funding to councils has been cut by almost 50%¹²⁵ which has put pressure on councils to spend less on care either through reducing the rates they pay providers or by reducing the number of people they fund. Because local authorities have a responsibility to revenue locally to subsidise the grant they receive from national government, those local authorities in more affluent areas are able to raise more¹²⁶. The result is wide variation in the eligibility for care between local areas, despite the intention of the Care Act (2014) being to standardise eligibility.

¹²² <https://publications.parliament.uk/pa/cm5801/cmselect/cmhealth/206/20602.htm>

¹²³ <https://www.nuffieldtrust.org.uk/news-item/other-types-of-support-how-do-the-countries-compare#support-for-health-needs>

¹²⁴ <https://www.kingsfund.org.uk/publications/social-care-360/expenditure>

¹²⁵ <https://www.nao.org.uk/wp-content/uploads/2018/07/Adult-social-care-at-a-glance.pdf>

¹²⁶ <https://www.ifs.org.uk/uploads/publications/bns/BN227appA.pdf>

5.3. Workforce

There is no national workforce strategy for the adult social care workforce - the last strategy was published by government over a decade ago in 2009.¹²⁷ The number of vacant posts in the English social care sector has climbed steadily since 2012/13, reaching 122,000 or 8% of the total workforce in 2019¹²⁸, with providers having difficulty recruiting and retaining workers, particularly to the roles of care worker, registered manager and nurse.¹²⁹ The sector also suffers from high staff turnover, poor working conditions, and 24% of the workforce are on zero-hours contracts¹³⁰. Pay is low and there are few opportunities for training and progression. The adult social care workforce is reliant on migrant labour. In total, an estimated 98,710 migrant workers joined the formal care workforce between 2009 and 2019¹³¹, with 9% from EU and 11% from non-EU countries. In London, more than two in five care workers are from abroad.¹³² Care workers have not been recognised as eligible for the ‘skilled worker’ route, in the forthcoming points-based immigration system, due to be implemented on January 1st, 2021¹³³.

There is a high level of reliance on informal carers. There are over five million adults providing unpaid care for older people in England.¹³⁴ National surveys of adult carers report increases in workload, responsibilities, and financial difficulties.¹³⁵ Support for carers includes a Carers Allowance set at £67.25 per week as of April 2020, administered by the Department for Work and Pensions.¹³⁶ However, access to this entitlement remains limited.¹³⁷ Given the challenges in the professional workforce, it is likely that there will be an increasing reliance on unpaid carers to fill the gaps.

5.4. Long-term care provider market

Care is provided by approximately 9,000 home care providers and over 15,000 care home providers. Around 78% of all adult care services are privately owned and run.¹³⁸ The Care Act 2014 places a duty on local authorities to ensure that there is diversity and quality in the market of care providers. However, due to the downward pressure on fees stemming from cuts to local authority budgets, many providers find that the fees paid by local authorities fall short of covering the full costs of providing care. People who fund their own care are being charged on average 41% more than local authority funded residents because of this shortfall.¹³⁹ It is increasingly common for care providers to go out of business, struggle to stay in business or hand back contracts to local authorities. A survey in 2019 found that some 75% of councils reported that these organisations had either closed or handed back contracts in

¹²⁷https://webarchive.nationalarchives.gov.uk/20130105063710/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_098481

¹²⁸<https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/national-information/The-size-and-structure-of-the-adult-social-care-sector-and-workforce-in-England.aspx>

¹²⁹<https://publications.parliament.uk/pa/cm201719/cmselect/cmpublic/690/690.pdf>

¹³⁰ *ibid*

¹³¹https://www.nuffieldtrust.org.uk/files/2019-12/1575384724_migration-election-briefing-web.pdf

¹³²<https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/documents/Regional-reports/Regional-report-London.pdf>

¹³³<https://www.gov.uk/government/publications/uk-points-based-immigration-system-further-details-statement>

¹³⁴https://www.sheffield.ac.uk/polopoly_fs/1.546409!/file/Valuing-Carers-2015.pdf

¹³⁵<https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2018-19>

¹³⁶https://www.nuffieldtrust.org.uk/news-item/what-are-carers-entitled-to#_ftn8

¹³⁷https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/779673/benefits-statistical-summary-february-2019.pdf

¹³⁸<https://www.skillsforcare.org.uk/Documents/About/sfcd/Economic-value-of-the-adult-social-care-sector-England.pdf>

¹³⁹<https://assets.publishing.service.gov.uk/media/5a1fdf30e5274a750b82533a/care-homes-market-study-final-report.pdf>

the last 6 months, creating enormous disruption and discontinuity for those receiving care.¹⁴⁰ Because of market fragility, the government has introduced market oversight and a failure regime covering financial as well as quality failure.¹⁴¹

Information systems

There is no national minimum dataset for care homes, or social care in England¹⁴². During the pandemic, the limited existing data was supplemented by data collections from several bodies (the NHS, providers themselves, the death registration system, Public Health England, and the regulator, CQC). Those working in the sector report that this has led to repeated collection of similar data, by multiple stakeholders. This reflects the lack of data and technology infrastructure in the social care sector, which by comparison with the health care sector in England and Wales, has received little investment.

The COVID-19 crisis has stimulated some technological innovation in care homes; for example the NHS has expanded the use of encrypted NHS email to care home staff, developed a web portal for Personal Protection Equipment (PPE) emergency procurement, and has piloted 'remote' social care interventions. Some care homes and General Practices (GP) have also used tablets and video calling to allow GP visits and to communicate with families. However, this is in the context of fundamental issues with capacity of the care home sector to engage in these initiatives due to a lack of infrastructure (e.g. broadband), or low usage of digital technology among home care staff.

At a provider and individual level, data and information sharing are limited. There have been several successful partnerships between the health and local authority sector across England to link social care data collected by councils with health care data. However, this only covers people whose social care provision is provided by local authorities, not those who pay themselves. There are no national datasets on social care utilisation or individual expenditure and the complex and fragmented nature of the provider market makes data collection difficult. The development of the Capacity Tracker¹⁴³ for care homes, mandated during Covid-19, is a welcome addition with potential to provide market intelligence, although there are concerns about the accuracy of data entered, with implications for planning and prioritisation in central government¹⁴⁴. It remains impossible to obtain an accurate estimate of the number of self-funders or total social care spend across all care settings.¹⁴⁵

6. Long-term care policy and practice measures to mitigate the impacts of COVID-19 in England

The Health Foundation has published a detailed report on the policies response to the COVID pandemic in social care¹⁴⁶. This section summarizes key policy measures.

¹⁴⁰ https://www.adass.org.uk/media/7295/adass-budget-survey-report-2019_final.pdf

¹⁴¹ <https://www.cqc.org.uk/guidance-providers/market-oversight-corporate-providers/market-oversight-adult-social-care>

¹⁴² <https://ltccovid.org/2020/05/14/the-invisibility-of-the-uk-care-home-population-uk-care-homes-and-a-minimum-dataset/>

¹⁴³ <https://www.necsu.nhs.uk/capacity-tracker/capacity-tracker-about-us/>

¹⁴⁴ https://www.laingbuisson.com/wp-content/uploads/2020/07/Covid-story_v5.pdf

¹⁴⁵ <https://www.nuffieldtrust.org.uk/news-item/adult-social-care-statistics-the-potential-for-change>

¹⁴⁶ <https://www.health.org.uk/publications/reports/adult-social-care-and-covid-19-assessing-the-policy-response-in-england>

6.1. Whole sector measures

6.1.1. National COVID-19 social care taskforce

On 8 June the Government announced the creation of a social care sector COVID-19 taskforce in order to ensure concerted action to implement key measures taken to date.¹⁴⁷ In particular, the taskforce was intended to support delivery of the Government's social care action plan published on the 15 April¹⁴⁸ and its home care support package.¹⁴⁹ The taskforce, which included representatives from across government and the care sector, was intended to 'support the national campaign to end transmission in the community and will also consider the impact of COVID-19 on the sector over the next year and advise on a plan to support it through this period'. The Taskforce published its report in late September 2020, identifying a total of 52 recommendations across a range of domains including PPE, testing, workforce and controlling infection in different settings¹⁵⁰.

6.1.2. Financial measures

The action plan for social care published on 15 April confirmed the announcement in March of £2.9 billion of funding 'to strengthen care for the vulnerable'.¹⁵¹ Of the 2.9 billion, £1.3 billion have been earmarked for collaborative efforts between NHS and local authorities, particularly to fund additional support following hospital discharge. £1.6 billion of the funding are allocated to support local government with the provision of services, including adult social care. The Action Plan outlines that local authorities are expected to use the additional funding to 'protect providers' cash flow, monitor ongoing cost of care delivery and 'adjust fees to meet new costs'.¹⁵² It is anticipated that this funding covers the cost for additional personal protective equipment (PPE) required.¹⁵³ Local authorities have been asked to provide information regarding the distribution of funding^{154,155}. Furthermore, the government suggests that the additional money provided could also be used for backfilling shifts as well as maintain income for workers unable to work due to physical distancing measures as far as possible. This is intended to financially support workers who may have to stop working temporarily because they are unwell or self-isolating. Furthermore, the plan made a plea for donations to support social care workers who may experience financial difficulties, similar to the donations that NHS charities have received.¹⁵⁶ The survey described above also examined funding access, and found that only 30% of care home

¹⁴⁷ <https://www.gov.uk/government/groups/social-care-sector-covid-19-support-taskforce>

¹⁴⁸ <https://www.gov.uk/government/news/national-action-plan-to-further-support-adult-social-care-sector>

¹⁴⁹ <https://www.gov.uk/government/publications/coronavirus-covid-19-support-for-care-homes/coronavirus-covid-19-care-home-support-package>

¹⁵⁰ <https://www.gov.uk/government/publications/social-care-sector-covid-19-support-taskforce-report-on-first-phase-of-covid-19-pandemic/social-care-sector-covid-19-support-taskforce-final-report-advice-and-recommendations>

¹⁵¹ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/879639/covid-19-adult-social-care-action-plan.pdf

¹⁵² <https://www.gov.uk/government/publications/coronavirus-covid-19-personal-protective-equipment-ppe-plan/covid-19-personal-protective-equipment-ppe-plan>

¹⁵³ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/879639/covid-19-adult-social-care-action-plan.pdf

¹⁵⁴ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/879639/covid-19-adult-social-care-action-plan.pdf

¹⁵⁵ <https://www.gov.uk/government/publications/coronavirus-covid-19-personal-protective-equipment-ppe-plan/covid-19-personal-protective-equipment-ppe-plan>

¹⁵⁶ <https://www.gov.uk/government/publications/coronavirus-covid-19-personal-protective-equipment-ppe-plan/covid-19-personal-protective-equipment-ppe-plan>

managers reported receiving a financial uplift at the time, with 73% stating that they needed more funding¹⁵⁷.

On 15 May a £600 million Infection Control Fund was introduced as part of a wider package of support for care homes to help providers reduce the rate of transmission in and between care homes and support wider workforce resilience.¹⁵⁸ The funding is being paid in 2 tranches. The first has been paid to local authorities on 22 May 2020. The second tranche is to be paid in early July.¹⁵⁹ This money has been allocated to Local Authorities and is in addition to the funding already provided to support Adult Social Care sector during the COVID-19 pandemic. Local authorities are expected to pass 75% of the initial funding directly to care homes in their area for use on infection control measures, including to care homes with whom the local authority does not have existing contracts. The second payment will be contingent on the first being used for infection control. The remaining 25% must also be used for infection control measures, however local authorities are able to allocate based on need.¹⁶⁰

Local authority directors responsible for administering this new fund have expressed “deep concern” that it apparently cannot be used by homes to purchase PPE, requires detailed and prescriptive accounting and reporting, does not cover domiciliary care and supported living schemes, resulting in “a confused and overly bureaucratic system which makes it difficult for providers to claim and impossible for local authorities to deliver within the required timescales”.¹⁶¹

The Local Government Association, however, has expressed concern that despite the additional funding they may not have sufficient funds to cover the additional costs for PPE needed as normal routes of funding, such as business rates and parking charges have been reduced during the lockdown.¹⁶² An independent analysis commissioned by local authorities estimates that providers face over £6bn in additional costs during April to September, because of higher staffing costs (mainly due to cover staff who are ill or self-isolating), PPE and extra cleaning and overhead costs.¹⁶³

In response to concerns that the fund was running out, the government announced a second round of infection control funding on 1st October 2020, with the second tranche to be paid in December 2020¹⁶⁴. The funding was accompanied by guidance that specified that a proportion of the support was to be allocated to providers other than care homes. This signalled a recognition that social care is delivered in a variety of settings, not just care homes. The second round also includes guidance on using the fund to support full sick pay of workers to receive flu vaccination or to self-isolate.¹⁶⁵

¹⁵⁷ Rajan, S., Comas-Herrera, A. and Mckee, M., 2020. Did the UK Government Really Throw a Protective Ring Around Care Homes in the COVID-19 Pandemic?. *Journal of Long-Term Care*, (2020), pp.185–195. DOI: <http://doi.org/10.31389/jltc.53>

¹⁵⁸ <https://www.gov.uk/government/news/care-home-support-package-backed-by-600-million-to-help-reduce-coronavirus-infections>

¹⁵⁹ <https://www.gov.uk/government/publications/adult-social-care-infection-control-fund/about-the-adult-social-care-infection-control-fund>

¹⁶⁰ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/885214/14_May_2020_-_MSC_letter_-_support_for_care_homes_1.pdf

¹⁶¹ <https://www.adass.org.uk/media/7909/200529-adass-letter-to-minister-of-state-re-infection-control-fund.pdf>

¹⁶² <https://www.bbc.co.uk/news/health-52284281>

¹⁶³ <https://www.local.gov.uk/lga-social-care-providers-face-more-ps6bn-extra-covid-19-costs>

¹⁶⁴ <https://www.gov.uk/government/publications/adult-social-care-infection-control-fund-round-2>

¹⁶⁵ <https://www.gov.uk/government/publications/adult-social-care-infection-control-fund-round-2/adult-social-care-infection-control-fund-round-2-guidance>

6.1.3. Oversight and regulation

The Coronavirus Act (25 March and renewed on 30 September 2020) included provision to relax the responsibilities of local authorities under the Care Act 2014 to streamline their services in case of workforce shortages or increased demand. The Act also enabled rapid discharge of patients from hospital by allowing assessments to be delayed^{166,167}. There was concern that the Care Act Easements included in the Coronavirus Act would be widely used to reduce care packages but, in the event, only a small number of councils utilised them¹⁶⁸. At time of writing, the CQC reports that no local authorities are currently using Care Act Easements¹⁶⁹.

The Care Quality Commission interrupted routine inspections on the 16 March¹⁷⁰. In May the CQC began to implement an Emergency Support Framework setting out its approach to regulation during COVID-19.¹⁷¹ This involved suspending routine inspections of services and instead using and sharing information to target support where it's needed and taking action to keep people safe and protect their human rights. CQC are now starting to resume some inspections in 300 random homes in relation to management of the pandemic, examining four key areas: Safe care & treatment; Staffing arrangements; Protection from abuse and Assurance processes, monitoring and risk management¹⁷². Much will be conducted remotely and in person inspections will take place under exceptional circumstances only.

6.1.4. Access to testing

There has been strong criticism of the Government's strategy for testing during the coronavirus crisis.¹⁷³ Limitations on testing capacity meant that initial workforce testing strategy focused on NHS workers with symptoms. This was extended to social care workers (with symptoms) from 15 April¹⁷⁴ and on 28 April, a policy of one-off whole home testing was announced for all staff and residents of care homes with residents over 65 or with dementia and an online portal was launched on 11 May to help care homes arrange deliveries of test kits.¹⁷⁵ Although testing capacity was increasing, this was not without problems. The BBC reported that on 22 April, 159 out of 210 care providers contacted about testing reported that none of their staff had received a test.¹⁷⁶ On 12 May, the Guardian reported that care home operators accused the government of 'a complete system failure' regarding the promised testing in care homes. According to this article only tens of thousands have been tested so far, leaving many vulnerable people at risk. Different government agencies are accused of passing responsibilities to each other.¹⁷⁷ A survey of 43 English care home managers, which was conducted at the end of May and early June 2020, found that only 40% had accessed testing of asymptomatic residents and 50% of asymptomatic staff. At that time, only 36% of residents had been tested, with many describing a chaotic

¹⁶⁶ <https://www.legislation.gov.uk/ukpga/2020/7/contents/enacted>

¹⁶⁷ <https://www.health.org.uk/publications/reports/adult-social-care-and-covid-19-assessing-the-policy-response-in-england>

¹⁶⁸ <https://www.communitycare.co.uk/2020/04/30/eight-councils-triggered-care-act-duty-moratorium-month-since-emergency-law-came-force/>

¹⁶⁹ <https://www.cqc.org.uk/guidance-providers/adult-social-care/care-act-easements-it>

¹⁷⁰ <https://www.cqc.org.uk/news/stories/routine-inspections-suspended-response-coronavirus-outbreak>

¹⁷¹ <https://www.cqc.org.uk/news/stories/joint-statement-our-regulatory-approach-during-coronavirus-pandemic>

¹⁷² <https://whiteleyvillage.org.uk/whiteleys-covid-19-response-effective-in-all-key-areas-says-cqc/>

¹⁷³ <https://www.ft.com/content/fa747fbd-c19e-4bac-9c37-d46afc9393fb>

¹⁷⁴ <https://www.gov.uk/government/news/government-to-offer-testing-for-everyone-who-needs-one-in-social-care-settings>

¹⁷⁵ <http://www.nationalhealthexecutive.com/Health-Care-News/government-portal-care-home-testing>

¹⁷⁶ <https://www.bbc.co.uk/news/health-52284281>

¹⁷⁷ <https://www.theguardian.com/society/2020/may/12/testing-coronavirus-uk-care-homes-complete-system-failure>

and poorly co-ordinated service¹⁷⁸. At that time, only 10% of care homes surveyed had successfully tested all residents in their care home¹⁷⁹.

On 8th June the Government announced that all remaining adult care homes would be able to access whole care home testing for all residents and asymptomatic staff through the digital portal, including adult care homes catering for adults with learning disabilities or mental health issues, physical disabilities, acquired brain injuries and other categories for younger adults under 65 years.¹⁸⁰ It should be noted that these ‘whole care home’ testing arrangements do not apply to supported living settings, extra care settings and domiciliary care. In these situations individual tests can be applied for through self-referral. From 3rd July, care home staff were promised weekly testing¹⁸¹, but domiciliary care staff are still only eligible for free testing if symptomatic, as the general population¹⁸².

In the light of advice from the Government’s Scientific Advisory Group for Emergencies (SAGE) and results from the Vivaldi 1 study, regular retesting staff and residents in care homes for over 65s and those with dementia was announced to be implemented from early July.¹⁸³ It has been reported that this has been delayed until September,¹⁸⁴ with promises of a new rapid point of care tests, although these have yet to be formally approved and questions remain about the most suitable and safe tests for such a vulnerable setting¹⁸⁵.

The Vivaldi 1 care homes survey asked care home staff to report on the total number of confirmed cases among staff and residents since the start of the pandemic.¹⁸⁶ A number of interesting conclusions emerged:¹⁸⁷

- Regular use of ‘bank’ staff (healthcare professionals who do temporary work in different settings as needed) is an important risk factor for infection in residents and staff.
- Staff are more likely to transmit infections to residents than vice versa.
- The number of new admissions, and return of residents to the care home from hospital, may be important risk factors for infection in residents and staff.

6.1.5 Access to personal protection equipment (PPE)

The Government has faced criticism and legal challenges for failures in the availability and distribution of PPE, particularly in the early phase of the pandemic. There was a significant shortage of PPE – face masks, aprons, gloves and visors and, furthermore, the central stockpile was designed for a flu

¹⁷⁸ <https://ltccovid.org/2020/06/09/learning-from-the-impacts-of-covid-19-on-care-homes-in-england-a-pilot-survey/>

¹⁷⁹ Rajan, S., Comas-Herrera, A. and Mckee, M., 2020. Did the UK Government Really Throw a Protective Ring Around Care Homes in the COVID-19 Pandemic?. *Journal of Long-Term Care*, (2020), pp.185–195. DOI: <http://doi.org/10.31389/jltc.53>

¹⁸⁰ <https://www.gov.uk/government/news/whole-home-testing-rolled-out-to-all-care-homes-in-england>

¹⁸¹ <https://www.gov.uk/government/news/regular-retesting-rolled-out-for-care-home-staff-and-residents>

¹⁸²

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/933134/Routes_for_Coronavirus_testing_in_adult_social_care_in_England_accessible1.pdf

¹⁸³ <https://www.gov.uk/government/news/regular-retesting-rolled-out-for-care-home-staff-and-residents>

¹⁸⁴ <https://www.thetimes.co.uk/past-six-days/2020-08-02/news/care-home-coronavirus-testing-pledge-abandoned-tqxf6mm6j>

¹⁸⁵ <https://www.gov.uk/government/news/roll-out-of-2-new-rapid-coronavirus-tests-ahead-of-winter#:~:text=Millions%20of%20new%20rapid%20coronavirus,and%20labs%20from%20next%20week.&text=Millions%20of%20ground%2Dbreaking%20rapid,testing%20capacity%20ahead%20of%20winter>

¹⁸⁶ <https://www.gov.uk/government/statistics/vivaldi-1-coronavirus-covid-19-care-homes-study-report>

¹⁸⁷ <https://www.gov.uk/government/publications/vivaldi-1-coronavirus-covid-19-care-homes-study-report/vivaldi-1-covid-19-care-homes-study-report>

pandemic.^{188,189} In the view of the British Medical Journal, the Government ‘failed to protect staff in the NHS and social care by not delivering sufficient amounts of personal protective equipment (PPE) of the right specification, again deviating from WHO advice’.¹⁹⁰ Directors in the social care sector specifically pointed to ‘a critical lack of PPE and testing of social care staff and service users is putting them at unnecessary risk of exposure’.¹⁹¹ Resentment about prioritisation of the NHS for distribution of PPE has been expressed.¹⁹²

Initial steps announced on 18 March included distribution of PPE to every care home and care home provider to ensure they had at least 300 fluid repellent face masks for immediate needs, followed by a further tranche of items of PPE in early April.¹⁹³ However, the government did acknowledge PPE supply shortages and published a PPE plan on 15 April with the goal that ‘everyone should get the personal protective equipment (PPE) they need’.¹⁹⁴ Announcements by the government about the number of items of PPE being delivered have been questioned. According to the BBC, over half of the 1.2bn items of PPE the Department of Health’s announced on 10 May for health and social care providers in England were surgical gloves, with gloves individually counted rather than in pairs¹⁹⁵ and faulty equipment subsequently being recalled¹⁹⁶. It is not clear how the protective equipment delivered was divided between health and social care and there have been suggestions that delivery systems have been failing to provide to care homes, requiring them to secure their own supplies individually. One example reported was that of a care provider who was provided with 400 face masks while requiring over 35,000 masks a week.¹⁹⁷ In the survey of English care homes at the end of May and early June mentioned above, 70% of care home managers reported insufficient PPE supplies, with 34% of providers purchasing supplies directly from abroad.

In the social care sector providers have traditionally organised the PPE they required through the market. The adult social care action plan announced that the Government was now stepping in with arrangements to support the supply and distribution of PPE.¹⁹⁸ A parallel supply chain has been established for emergency PPE provision, involving new logistics networks and support from the army and including a national supply disruption response (NSDR) system to respond to emergency PPE requests and a 24/7 helpline for providers who have an urgent requirement.¹⁹⁹

¹⁸⁸ <https://www.nao.org.uk/wp-content/uploads/2020/06/Readying-the-NHS-and-adult-social-care-in-England-for-COVID-19.pdf>

¹⁸⁹ <https://goodlawproject.org/news/the-ppe-fiasco/>

¹⁹⁰ <https://www.bmj.com/content/369/bmj.m1932>

¹⁹¹ <https://www.adass.org.uk/statement-by-adass-and-unions-on-ppe-in-the-care-sector>

¹⁹² <https://www.ft.com/content/6afb06d6-abd6-4281-ac16-74f500f096d0>

¹⁹³ <https://www.gov.uk/government/publications/coronavirus-covid-19-personal-protective-equipment-ppe-plan/covid-19-personal-protective-equipment-ppe-plan>

¹⁹⁴ <https://www.gov.uk/government/publications/coronavirus-covid-19-personal-protective-equipment-ppe-plan/covid-19-personal-protective-equipment-ppe-plan>

¹⁹⁵ <https://www.bbc.co.uk/news/health-52254745>

¹⁹⁶ <https://www.carehomeprofessional.com/recall-notice-issued-for-faulty-ppe-masks-sent-to-care-homes/>

¹⁹⁷ <https://www.theguardian.com/world/2020/may/09/uk-care-homes-scramble-to-buy-their-own-ppe-as-national-deliveries-fail>

¹⁹⁸ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/879639/covid-19-adult-social-care-action-plan.pdf

¹⁹⁹ <https://www.gov.uk/government/publications/coronavirus-covid-19-personal-protective-equipment-ppe-plan/covid-19-personal-protective-equipment-ppe-plan>

On the 25 June the Government announced that two billion items of PPE have been delivered to NHS and social care staff across England since the start of the COVID-19 outbreak.²⁰⁰ No breakdown by sector is available.

6.1.6. Supporting care sector staff

The social care action plan recognised the urgent need to increase the social care workforce during the pandemic 'to cover for those who are not in work, and to relieve the pressure on those that are'. The action plan included an 'ambition' to attract 20,000 people into social care over the next 3 months.²⁰¹ It is unclear what progress has been made towards achieving this ambition.

The Infection Control Fund aims to ensure that all care workers isolating in line with guidance continue to receive their full wages and face no loss of income²⁰². Beyond this however, no specific financial support has been offered to social care workers in England, unlike their counterparts in Wales, where the Welsh Government announced that social care workers will each receive a bonus payment of £500 if they have been asked to self-isolate, at a total cost of £32.2m. First Minister of Wales, Mark Drakeford said: "I want our social care workforce to know their hard work is both appreciated and recognised".²⁰³ In Scotland, the government introduced a 3.3% pay increase for care workers, backdated from 1st April 2020, ensuring that all care workers providing direct care receive at least the Real Living Wage²⁰⁴.

On 6th May the Government launched a dedicated CARE app to support the social care workforce during COVID-19, offering access to guidance, learning resources, discounts and other support all in one place.²⁰⁵ This was followed by more detailed guidance on the health and wellbeing of the adult social care workforce on 11th May.²⁰⁶

On 15th May, the Government announced a new wellbeing package for social care staff delivered through the CARE app including 2 new helplines, led by the Samaritans and Hospice UK. This is intended to help support care staff with their mental health and wellbeing and support those who have experienced a traumatic death as part of their work or help with anxiety and stress.²⁰⁷ Social care staff were designated as 'key workers' on 19th March to enable them to continue to access childcare once schools were closed²⁰⁸.

6.2. Care homes (including supported living, residential and nursing homes, skilled nursing facilities)

Guidance on Infection Prevention and Control for care homes was updated numerous times during the pandemic. Some of the relevant guidance was issued in policy documents from the Department of

²⁰⁰ <https://www.gov.uk/government/news/major-milestone-hit-as-2-billion-items-of-ppe-delivered>

²⁰¹ <https://www.gov.uk/government/publications/coronavirus-covid-19-adult-social-care-action-plan>

²⁰² <https://www.gov.uk/government/publications/adult-social-care-infection-control-fund-round-2/adult-social-care-infection-control-fund-round-2-guidance>

²⁰³ <https://www.bbc.co.uk/news/uk-wales-52502325>

²⁰⁴ <https://www.gov.scot/news/pay-rise-for-social-care-staff/>

²⁰⁵ <https://www.gov.uk/government/news/dedicated-app-for-social-care-workers-launched>

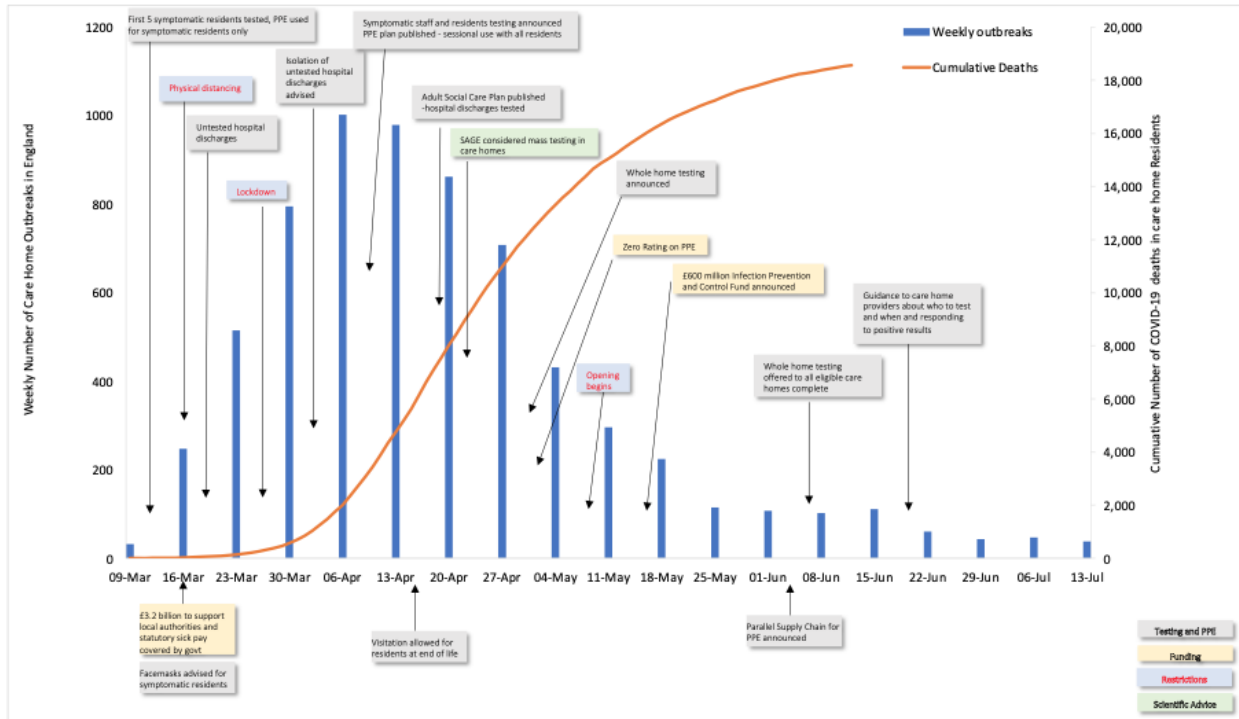
²⁰⁶ <https://www.gov.uk/government/publications/coronavirus-covid-19-health-and-wellbeing-of-the-adult-social-care-workforce/health-and-wellbeing-of-the-adult-social-care-workforce>

²⁰⁷ <https://www.gov.uk/government/news/care-home-support-package-backed-by-600-million-to-help-reduce-coronavirus-infections#history>

²⁰⁸ <https://www.gov.uk/government/publications/coronavirus-covid-19-maintaining-educational-provision/guidance-for-schools-colleges-and-local-authorities-on-maintaining-educational-provision>

Health and Social Care, and some from Public Health England. Initial guidance on 25 February advised that it was unlikely that people receiving care would be infected (at the time there had not been no known transmission within the UK)²⁰⁹. It was not until April that the guidance documents in England took into account the possibility of pre-symptomatic or asymptomatic transmission both with regards testing and isolation policies²¹⁰.

Figure 7. Timeline of measures adopted in relation care homes, compared to number of outbreaks and cumulative deaths



Source: Adapted from Rajan et al²¹¹.

6.2.1. Prevention of COVID19 infections

Key vectors for COVID-19 infections in care homes are new admissions (or residents who return after a hospital stay), staff and visitors.

Infections from family and other visitors

²⁰⁹ <https://www.gov.uk/government/publications/guidance-for-social-or-community-care-and-residential-settings-on-covid-19/guidance-for-social-or-community-care-and-residential-settings-on-covid-19>

²¹⁰ <https://itccovid.org/2020/06/12/asymptomatic-and-pre-symptomatic-transmission-in-uk-care-homes-and-infection-prevention-and-control-ipc-guidance-an-update/>

²¹¹ Rajan, S., Comas-Herrera, A. and Mckee, M., 2020. Did the UK Government Really Throw a Protective Ring Around Care Homes in the COVID-19 Pandemic?. Journal of Long-Term Care. DOI: <http://doi.org/10.31389/jltc.53>,

data sources: <https://www.gov.uk/government/statistical-data-sets/covid-19-number-of-outbreaks-in-care-homes-management-information> and <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deaths-involving-covid-19-in-the-care-sector-england-and-wales/deaths-occurring-up-to-12-june-2020-and-registered-up-to-20-june-2020-provisional#deaths-involving-covid-19-among-care-home>

The initial guidance in England (13 March) advised against visits of people who had suspected COVID-19 or were feeling unwell. The main care home chains stopped non-essential visits around that time. Although no formal ban on visits to care homes was issued, the advice was not to visit except in exceptional (usually end of life) situations²¹² and the Prime Minister also announced on March 16th that the physical distancing measures should also apply to care homes. Guidance on family visits was issued on the 22 July, linking the visiting policy to local levels of risk of transmission and advising that visits are limited to a “single constant visitor”²¹³.

Following the announcement of the second national lockdown, more than 60 care organisations collectively called on 03rd November for safe visits to care homes to continue; a similar call was made by ADASS²¹⁴. The Department of Health and Social Care is exploring options to safely allow visits. On 13th October 2020 the Care Minister announced the government’s intention to pilot a care home visitor scheme, in which designated visitors would be recategorized as ‘key workers’ and given priority access to weekly rapid antigen tests and PPE^{215,216}. While tentatively welcomed by some campaigning groups, the pilot has been slow to launch, and is expected to commence on 16th November 2020 in 20 care homes across four local authority areas, although other independent pilots are already starting to report encouraging results, using in house PCR tests for relatives²¹⁷.

In response to the ongoing restrictions, a high court judge ruled on 3rd November that visits to care homes were legal²¹⁸. Following this, government guidance on visiting arrangements were updated on 5th November 2020, advising directors of public health and providers to facilitate visiting where possible in a “risk-managed way”²¹⁹. There is ongoing concern as to whether the arrangements are sufficiently flexible and sensitive to the needs of people in care homes and their families.

Infections from new admissions or hospital discharges

One of the most controversial policy decisions taken at an early stage in the management of the coronavirus crisis was the rapid discharge of older patients from hospitals to care homes around the country without testing for COVID-19. The British Medical Journal has referred to this as a ‘reckless policy’²²⁰, a sentiment echoed by the Public Accounts Committee.²²¹ On 17 March, Simon Stevens, the Chief Executive of the NHS, instructed managers to urgently discharge all hospital patients who were medically fit to leave in order to free up substantial numbers of hospital beds.²²² Discharges – including to care homes – may already have been taking place at this point in readiness for the expected surge in COVID-19 admissions.

²¹² <https://www.bbc.co.uk/news/52674073>

²¹³ <https://www.gov.uk/government/publications/visiting-care-homes-during-coronavirus/update-on-policies-for-visiting-arrangements-in-care-homes>

²¹⁴ <https://www.laingbuissonnews.com/care-markets-content/news/organisations-call-for-care-home-visits-to-continue/>

²¹⁵ <https://committees.parliament.uk/oralevidence/1032/pdf/>

²¹⁶ <https://www.bbc.co.uk/news/uk-politics-54528021>

²¹⁷ <https://www.bbc.co.uk/news/health-54843815>

²¹⁸ https://www.theguardian.com/society/2020/nov/03/judge-says-care-home-residents-in-england-are-legally-allowed-visitors?fbclid=IwAR1EHVzBhTUH1E7IFqzu9eYzCN7nMnkpT8Mlxhwoygl7tHQgl_gIve2cok4

²¹⁹ <https://www.gov.uk/government/publications/visiting-care-homes-during-coronavirus/update-on-policies-for-visiting-arrangements-in-care-homes>

²²⁰ <https://www.bmj.com/content/369/bmj.m1932>

²²¹ https://publications.parliament.uk/pa/cm5801/cmselect/cmpubacc/405/40503.htm#_idTextAnchor000

²²² <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/urgent-next-steps-on-nhs-response-to-covid-19-letter-simon-stevens.pdf>

Guidance issued on 19 March 2020 In support of hospital discharge arrangements, announced that the existing North of England Commissioning Support (NECS) care home tracker – designed to facilitate rapid search for available capacity in care homes - would be expanded to cover all care homes across England.²²³ All care home providers were to sign up and use the tracker to identify vacancies from Monday 23 March 2020. Even if the available care home was not their first choice, patients were to be moved to a care home as soon as possible and could be moved to their preferred care home as soon as possible. The guidance also outlined funding to provide care for people discharged from hospital into institutional care settings irrespective of whether a care assessment had been completed or where their ordinary residence was. Care homes were to receive funding out of the NHS COVID-19 budget to expand their capacity to provide care. Funding to support people leaving hospital was renewed in August with £588m being allocated to the NHS to pay for additional support and rehabilitation for up to 6 weeks.²²⁴

At this time testing capacity was limited and available primarily for patients in critical care and those requiring hospital admission with symptoms of pneumonia, acute respiratory stress syndrome or flu like illness. The guidance of 2 April was explicit that ‘Negative tests are not required prior to transfers / admissions into the care home’.²²⁵ The National Audit Office estimated that around 25,000 people were discharged from hospitals to care homes between 17 March and 15 April²²⁶, using an approach which also accounted for discharges for new as well as existing residents of care homes, the Health Foundation estimated that, for the period of 17 March to 30 April, 46,700 people had been discharged to care homes, 7,700 fewer than in previous years²²⁷. However, the pattern of discharges differed between residential care and nursing homes. While residential care homes saw a decrease in discharges (with 12,400 discharges) compared to previous years, nursing homes saw an increase with 17,000 discharges²²⁸. National bodies representing care homes have complained about homes being pressured to accept residents that had not been tested²²⁹. The guidance of 2 April stated that ‘patients can be safely cared for in a care home if this guidance is followed’²³⁰. However, one senior hospital clinician has acknowledged that it was a ‘major error’ to assume ‘that care homes could cope with isolating patients and infection control measures in the same way a hospital could’.²³¹ It has been reported that the Care Quality Commission has been informed by care home managers that several hospitals discharged people to their care home despite suspecting – or even knowing – they were infected²³². NHS Providers – the membership organisation for NHS hospitals – has strongly rejected the suggestion that hospitals ‘knowingly’ transferred infected patients to care homes but do acknowledge that some asymptomatic patients may have been transferred early though ‘not in large numbers’²³³. It has been claimed that the initial discharge of older people back into care homes without prior COVID-19 testing to ensure that

²²³https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/880288/COVID-19_hospital_discharge_service_requirements.pdf

²²⁴ <https://www.gov.uk/government/news/more-than-half-a-billion-pounds-to-help-people-return-home-from-hospital>

²²⁵ <https://www.northamptonshire.gov.uk/coronavirus-updates/Documents/covid-19-care-homes-guidance.pdf>

²²⁶ <https://www.nao.org.uk/wp-content/uploads/2020/06/Readying-the-NHS-and-adult-social-care-in-England-for-COVID-19.pdf>

²²⁷ <https://reader.health.org.uk/adult-social-care-and-covid-19-assessing-the-impact-on-social-care-users-and-staff-in-england-so-far/key-points>

²²⁸ <https://reader.health.org.uk/adult-social-care-and-covid-19-assessing-the-impact-on-social-care-users-and-staff-in-england-so-far/key-points>

²²⁹ <https://www.carehome.co.uk/news/article.cfm/id/1623968/Anger-amongst-care-home-owners-told-to-accept-people-with-coronavirus>

²³⁰ <https://www.northamptonshire.gov.uk/coronavirus-updates/Documents/covid-19-care-homes-guidance.pdf>

²³¹ <https://www.ft.com/content/cd62bbf0-a73a-11ea-92e2-cbd9b7e28ee6>

²³² <https://www.dailymail.co.uk/news/article-8302039/Hospitals-probed-sending-elderly-care-homes-despite-KNOWING-coronavirus.html>

²³³ <https://nhsproviders.org/media/689548/spotlight-on-recent-discharges-into-care-homes-nhs-providers.pdf>

they were not infected is among the factors contributing to the high number of COVID-19 cases (and deaths) in care homes²³⁴. However, evidence is lacking for any accurate assessment of the extent to which hospital discharges in this period led to transmission of infection into care homes and genomic analyses suggest multiple routes of ingress into care homes²³⁵.

There has been some dispute about the trends in hospital discharge numbers during this critical period. Prime Minister Boris Johnson has stated that the “number of discharges from NHS into care homes went down by 40 per cent from January to March. It’s just not true there was some concerted effort to move people out of the NHS into care homes.”²³⁶ At the same time, detailed analysis of the data has revealed that, compared to the same period in the previous year, there was an increase in discharges to care homes in the first half of March and although there was an overall reduction in hospital discharges, discharges to care homes were increasing as a proportion of all discharges in late March and early April.²³⁷

In its COVID-19 adult social care action plan published on 15 April the government declared that it was ‘mindful that some care providers are concerned about being able to effectively isolate COVID-positive residents’ and in this context set out the commitment to test all residents prior to their admission to care homes, including on discharge from hospital.²³⁸ In cases where the results of the test cannot be obtained in time for discharge, patients should be cared for in isolation as if they had tested positive for COVID-19. Asymptomatic patients who have tested negative should also be cared for in isolation for 14 days. The same was recommended for patients with COVID-19 symptoms and a positive test result where the patient needed to be discharged from acute NHS care within the 14-day period since the beginning of the symptoms. The action plan recognised that not all providers will be able to accommodate these individuals through appropriate isolation or cohorted care (a reality supported by the survey of 43 English care home managers²³⁹), and in these circumstances the individual’s local authority will be asked to secure alternative appropriate accommodation and care for the remainder of the required isolation period. For admissions from the community, it is assumed they will be tested prior to admission and in consultation with the family, the care home can decide whether isolation is appropriate.

Infections from staff

Regular use of “bank” staff (professionals who do temporary work in different settings as needed) was identified as an important risk factor for infections in residents and staff by the Vivaldi study²⁴⁰. As described above, on the 28 of April it was announced that care home staff (and residents) would be able to access tests irrespective of whether they had symptoms²⁴¹. Prior to this, the guidance had been for

²³⁴ <https://www.liverpool.ac.uk/media/livacuk/publicpolicyamppractice/covid-19/PB011.pdf>

²³⁵ <https://www.gov.uk/government/publications/scwg-covid-19-and-care-homes-update-paper-23-september-2020>

²³⁶ <https://www.parliamentlive.tv/Event/Index/8e8e5214-346d-4be8-adf7-addfc839ff6d>

²³⁷ <https://www.hsj.co.uk/policy-and-regulation/discharges-to-care-homes-increased-year-on-year-during-critical-period/7027765.article>

²³⁸ <https://www.gov.uk/government/publications/coronavirus-covid-19-adult-social-care-action-plan>

²³⁹ Rajan, S., Comas-Herrera, A. and Mckee, M., 2020. Did the UK Government Really Throw a Protective Ring Around Care Homes in the COVID-19 Pandemic?. *Journal of Long-Term Care*, (2020), pp.185–195. DOI: <http://doi.org/10.31389/jltc.53>

²⁴⁰ <https://www.gov.uk/government/publications/vivaldi-1-coronavirus-covid-19-care-homes-study-report/vivaldi-1-covid-19-care-homes-study-report>

²⁴¹ <https://www.gov.uk/government/speeches/health-and-social-care-secretarys-statement-on-coronavirus-covid-19-28-april-2020>

staff simply to self-isolate if they (or a family member) displayed symptoms²⁴², putting further pressure on an already-stretched workforce²⁴³. Guidance published on the 9 July advises that staff work in only one care home if possible²⁴⁴.

6.2.2. Controlling spread once infection is suspected or has entered a facility

The key measures to control the spread of infection once it has entered require that any residents or staff who have the infection are identified and isolated. There have been two major difficulties in doing this effectively in care homes in England. First, guidance issued to care homes focused only on people who were displaying symptoms (initial guidance only mentioned a persistent cough and fever as symptoms), it took a long time for official guidance to consistently recognize the potential for pre-symptomatic or asymptomatic transmission²⁴⁵. Guidance on identifying residents and staff who may have been in contact with persons who had the virus and preventive isolation became available on the 2nd of April²⁴⁶.

The ability of care homes to implement existing IPC guidance was hampered by lack of access to testing (tests for asymptomatic residents and staff only started to be available after the 28 April), PPE, staff shortages and facilities that were not suitable for effective isolation or cohorting²⁴⁷. Where care homes are not able to implement adequate isolation or cohort policies, it is the responsibility of the local authority to secure alternative accommodation for the isolation period, drawing on the £1.3 billion discharge funding²⁴⁸.

6.2.3. Provision of health care and palliative care in care homes during COVID-19

During March and April, there was a substantial reduction in hospital admissions among care home residents. Elective admissions reduced to 58% of the 5-year historical average and emergency admissions to 85% of the 5-year historical average. By reducing admissions, care home and NHS teams may have reduced the risk of transmission, but there may have also been an increase in unmet health needs²⁴⁹.

To facilitate access to crucial medicines, on 23 April the Department of Health and Social Care issued new standard operating procedures for the use of medicine in care homes and hospice settings in England. The scheme allowed care homes and hospices to re-use medicine that was issued for one resident for another under specific circumstances and only in crisis situations. The guidance document contains information on the specific circumstances in which medicines labelled for one person (who no longer needs them) can be used for another person. The usually strict regulations around re-using or

²⁴² <https://www.gov.uk/government/publications/coronavirus-covid-19-adult-social-care-action-plan/covid-19-our-action-plan-for-adult-social-care#controlling-the-spread-of-infection-in-care-settings>

²⁴³

²⁴⁴ <https://www.gov.uk/government/publications/coronavirus-covid-19-support-for-care-homes/coronavirus-covid-19-care-home-support-package>

²⁴⁵ <https://ltccovid.org/2020/06/12/asymptomatic-and-pre-symptomatic-transmission-in-uk-care-homes-and-infection-prevention-and-control-ipc-guidance-an-update/>

²⁴⁶ <https://www.gov.uk/government/publications/coronavirus-covid-19-admission-and-care-of-people-in-care-homes/coronavirus-covid-19-admission-and-care-of-people-in-care-homes>

²⁴⁷ Rajan, S., Comas-Herrera, A. and Mckee, M., 2020. Did the UK Government Really Throw a Protective Ring Around Care Homes in the COVID-19 Pandemic?. *Journal of Long-Term Care*. DOI: <http://doi.org/10.31389/jltc.53>

²⁴⁸ <https://www.gov.uk/government/news/2-9-billion-funding-to-strengthen-care-for-the-vulnerable>

²⁴⁹ <https://www.health.org.uk/publications/reports/adult-social-care-and-covid-19-assessing-the-impact-on-social-care-users-and-staff-in-england-so-far>

recycling medication were relaxed as there were ‘increasing concerns about the pressure that could be placed on the medicines supply chain during the peak of the COVID-19 pandemic’²⁵⁰.

From the 15 of May, the NHS was expected to ensure that, care homes were able to receive clinical support from primary care and community health services. This should entail:

- timely access to clinical advice for staff and residents, a named clinical lead for every care home and weekly check-ins;
- proactive support for people living in care homes, including through personalised care and support planning as appropriate;
- support for care home residents with suspected or confirmed COVID-19 through remote monitoring (and face-to-face assessment where clinically appropriate) by a multidisciplinary team where practically possible (including those for whom monitoring is needed following discharge from either an acute or step-down bed); and;
- sensitive and collaborative decisions around hospital admissions for care home residents if they are likely to benefit²⁵¹.

6.2.4. Financial impact on care home providers

There are concerns about the viability of some care home providers, due to lower occupancy rates (as a result of high number of deaths and people putting off entering care homes), and higher costs linked to additional staffing and PPE expenditure. Analysis by the Care Quality Commission published in July 2020 shows that there has been a substantial reduction in admissions to care homes during the pandemic, although the rates vary significantly. Admissions funded by local authorities for week ending 7 June 2020 were on average of 72% (range 43 to 113%) of the number received in the same period in 2019. In contrast, self-funded admissions, were on average at 35% of 2019 levels (25% to 51%)²⁵². Some sources have estimated that occupancy of care home beds dropped 13% over the course of the pandemic²⁵³.

6.3. Community-based care

Many community-based care services, such as day care, have been interrupted as a result of the COVID-19 pandemic. Guidance on safe delivery of day care has been published by the Social Care Excellence Institute on the 10 July²⁵⁴.

It is likely that there have been reductions in the use of domiciliary care services, such as home care, as a result of people fearing contagion through contact with staff, and as a result of staff shortages due to their own need to self-isolate or shielding. Lack of access to PPE and testing for home care providers may have exacerbated this problem. There is no data yet on the extent to which services have been reduced or the degree to which this has affected the people who rely on those services and their family and other unpaid carers although a national survey by the Association of Directors of Adult Services

²⁵⁰https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/881838/medicines-reuse-in-care-homes.pdf

²⁵¹<https://www.gov.uk/government/publications/coronavirus-covid-19-support-for-care-homes/coronavirus-covid-19-care-home-support-package#stepping-up-nhs-clinical-support>

²⁵²<https://www.cqc.org.uk/sites/default/files/20200715%20COVID%20IV%20Insight%20number%203%20slides%20final.pdf>

²⁵³https://www.laingbuisson.com/wp-content/uploads/2020/07/Covid-story_v5.pdf

²⁵⁴<https://www.scie.org.uk/care-providers/coronavirus-covid-19/day-care/safe-delivery>

reported substantial increases in social care need arising from the unavailability of services, hospital discharge, carer breakdown and concerns about abuse and safeguarding.²⁵⁵

Guidance for home care providers was provided relatively late in the pandemic. On 27 April Public Health England issued guidance on PPE use for care workers providing domiciliary care. In addition to hand hygiene, respiratory hygiene and avoiding touching their face, care workers should also follow standard infection prevention and control precautions²⁵⁶.

The Government published wider guidance for domiciliary care providers on 22 May, much later than equivalent guidance for other long-term care settings was issued²⁵⁷. This covered PPE, shielding of clinically vulnerable people, hospital discharge and government and local authority support. The guidance has continued to be updated, including advice for providers to divide the people they care for into 'care groups' and allocate teams of staff to provide care specifically to those care groups²⁵⁸.

Data from a survey by the Care Quality Commission showed that, as of the 2 to 8 May, around a fifth of agencies were caring for at least one person with suspected or confirmed COVID-19²⁵⁹. Providers also reported that access to PPE was a big concern, with many instances of wrong or poor quality items being delivered. While homecare services are experiencing lower levels of activity (homecare hours at 94% of pre-pandemic levels), Local Authorities have continued to pay for planned hours, which has helped protect the providers they commission from, from the decrease in activity²⁶⁰.

In the absence of rapid and adequate support to the domiciliary care sectors, many providers have turned to local initiatives to continue to deliver care in a safe way, for instance through the use of remote monitoring technologies²⁶¹. Providers have furthermore reported improved relationships with the healthcare sector, with a more collaborative approach to supporting vulnerable individuals over the course of the pandemic²⁶².

6.4. Measures to support unpaid carers

The Action Plan recognised that unpaid carers were likely to provide even more support during this time of physical distancing and that respite services that have previously supported them are no longer available. It further acknowledged that carers' 'long-term health and wellbeing is critical to the sustainability of the social care system'. The needs of young carers were acknowledged, and tailored advice collaboratively developed with young carer is expected to become available²⁶³.

²⁵⁵ <https://www.adass.org.uk/media/7967/adass-coronavirus-survey-report-2020-no-embargo.pdf>

²⁵⁶ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/881296/Domiciliary_care_guidance_final.pdf

²⁵⁷ <https://www.gov.uk/government/publications/coronavirus-covid-19-providing-home-care/coronavirus-covid-19-provision-of-home-care>

²⁵⁸ <https://www.gov.uk/government/publications/coronavirus-covid-19-providing-home-care/coronavirus-covid-19-provision-of-home-care#shielding-and-care-groups>

²⁵⁹ <https://www.cqc.org.uk/sites/default/files/20200501%20COVID%20IV%20update%20number%201%20ACCESSIBLE.pdf>

²⁶⁰ <https://www.cqc.org.uk/sites/default/files/20200715%20COVID%20IV%20Insight%20number%203%20slides%20final.pdf>

²⁶¹ E.g, <https://www.carecity.london/your-blog/221-expert-care-in-covid-19>

²⁶² Nuffield Trust, forthcoming

²⁶³ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/879639/covid-19-adult-social-care-action-plan.pdf

The government further issued guidance for unpaid carers, which recommends carers to develop and emergency plan with the person they care for in case the carer becomes unable to continue to provide support, to follow hygiene rules, to maintain their own health and advice on how to react in case the person with care needs or the carer themselves develop symptoms of COVID-19²⁶⁴.

As recently as 03rd November 2020, 75 care organisations called on government to align the Carers Allowance with Universal Credit, as it is currently in Scotland, to recognise the disproportionate impact of the pandemic on carers^{265,266}.

6.4.1. Guidance for unpaid carers of adults with learning disabilities and autism

Guidance for unpaid carers of adults with learning disabilities and autistic adults is very similar to the general advice for unpaid care (published on 24 April). There are, however, specific points raised around communication and coping with bereavement²⁶⁷.

6.4.2. Digital support for unpaid carers

A press release by the Department of Health and Social Care (24 April) described that they, together with the Ministry for Housing Communities and Local Government have awarded up to £25,000 to 18 innovative digital solutions as part of the TechForce19 challenge. Among these, one app that received funding aims to ‘help carers identify health risks and deterioration within elderly communities’²⁶⁸.

Research accompanying the virtual Cuppa project, which offered unpaid carers the possibility to connect virtually for half an hour on weekdays with others in similar situations facilitated by a professional carer coach. The research found that over time carers developed friendships with other members of participating in the project, shared resources and experience and that the virtual Cuppa group became ‘a resource in its own right to develop individual resilience’. (p.22)²⁶⁹

6.5. Measures to mitigate the impacts on people with intellectual disabilities and people with autism

As evidenced throughout this report, much of the government social care guidance, including provision of support in the forms of PPE and COVID-19 testing, has focused on older people in nursing and residential care homes. Only 4.4% of adults with learning disabilities using long-term social care in England in 2018-19 were older adults living in nursing or residential homes²⁷⁰, with substantial numbers of working age adults (17.1%) living in nursing or residential care homes and the majority of adults living with family or in some form of supported housing. Government guidance for supported living services

²⁶⁴ <https://www.gov.uk/government/publications/coronavirus-covid-19-providing-unpaid-care/guidance-for-those-who-provide-unpaid-care-to-friends-or-family>

²⁶⁵ <https://www.disabilityrightsuk.org/news/2020/november/75-organisations-again-call-government-make-carer%E2%80%99s-allowance-fairer-carers>

²⁶⁶ <https://www.nuffieldtrust.org.uk/news-item/what-are-carers-entitled-to>

²⁶⁷ <https://www.gov.uk/government/publications/covid-19-providing-unpaid-care-to-adults-with-learning-disabilities-and-autistic-adults>

²⁶⁸ <https://www.gov.uk/government/news/digital-innovations-tested-to-support-vulnerable-people-during-covid-19-outbreak>

²⁶⁹ http://circle.group.shef.ac.uk/wp-content/uploads/2020/11/007_Aspect-Virtual-Cuppa-Report-4-compressed.pdf

²⁷⁰ <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2018-19>

was withdrawn on 13th May 2020²⁷¹ and was not replaced until 6th August, with the latest version updated on 5th November²⁷²; guidance on home care is available and was last updated on 4th November 2020²⁷³. There is also government guidance concerning direct payments, last updated on 18th November 2020²⁷⁴. An audit of residential care and supported living providers for 11,830 working age adults with intellectual disabilities and autistic people co-ordinated by the Voluntary Organisations Disability Group on 21st April 2020 reported very low levels of COVID-19 testing amongst staff or people using services, high staff sickness rates, and problems with accessing PPE²⁷⁵.

Government guidance for care staff supporting adults with intellectual disabilities and autistic adults²⁷⁶ was last updated on 5th November 2020, which links to a range of other relevant guidance and resources. This includes more detailed guidance from the Social Care Institute for Excellence on supporting autistic people and people with intellectual disabilities, including guidance for social workers and occupational therapists, guidance for care staff, and guidance for carers and family²⁷⁷.

The adult social care COVID-19 taskforce reported in late September 2020, identifying 52 recommendations across a range of domains including PPE, testing, workforce and controlling infection in different settings²⁷⁸. The learning disabilities and autistic people advisory group to this taskforce put forward 5 key recommendations (see below)²⁷⁹, which the co-chairs of the advisory group have stated were not reflected in the taskforce report as a whole:

1. Accessible guidance and communications
2. Restoring and maintaining vital support services
3. Expanding PPE and testing
4. Tackling isolation and loneliness
5. Seeking and supporting people who may be in crisis

Government guidance has not always been accompanied by accessible versions for people with intellectual disabilities, autistic people, and family members, and several NGOs (including some financially supported by the government for this purpose) have been producing easy-read and other accessible information, resources and guidance²⁸⁰.

²⁷¹ <https://www.gov.uk/government/publications/covid-19-residential-care-supported-living-and-home-care-guidance>

²⁷² <https://www.gov.uk/government/publications/supported-living-services-during-coronavirus-covid-19/covid-19-guidance-for-supported-living>

²⁷³ <https://www.gov.uk/government/publications/coronavirus-covid-19-providing-home-care/coronavirus-covid-19-provision-of-home-care>

²⁷⁴ <https://www.gov.uk/government/publications/coronavirus-covid-19-guidance-for-people-receiving-direct-payments>

²⁷⁵ <https://www.vodg.org.uk/news/new-data-from-adult-social-care-providers-reveals-urgent-need-to-better-support-disabled-people-and-their-services-through-the-coronavirus-covid-19-pandemic/>

²⁷⁶ <https://www.gov.uk/government/publications/covid-19-supporting-adults-with-learning-disabilities-and-autistic-adults/coronavirus-covid-19-guidance-for-care-staff-supporting-adults-with-learning-disabilities-and-autistic-adults>

²⁷⁷ <https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism>

²⁷⁸ <https://www.gov.uk/government/publications/social-care-sector-covid-19-support-taskforce-report-on-first-phase-of-covid-19-pandemic/social-care-sector-covid-19-support-taskforce-final-report-advice-and-recommendations>

²⁷⁹

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/919162/6_People_with_Learning_Disabilities_and_Autistic_People_Advisory_Group_report_accessible.pdf

²⁸⁰ <https://www.learningdisabilityengland.org.uk/what-we-do/keeping-informed-and-in-touch-during-coronavirus/information-and-guidance/>

7. Looking forward – policies and prospects for long term care

As well as COVID-19, long term care services also face the usual ‘winter pressures’ arising from cold weather and seasonal flu and other viral illnesses, particularly affecting older people and others with long term health conditions. The withdrawal of the UK from the EU on 1st January 2020 creates additional uncertainty for long term care services because of the potential impact on the supply of goods and services, workforce and the public finances²⁸¹. This has prompted fresh concerns about the resilience and readiness of long-term care services in responding to these multiple challenges.

Further policy efforts have been made to maintain and improve the capability of long-term care services as winter approaches. In June the government appointed a national Social Care Sector COVID-19 Support Taskforce to help reduce transmission in care services, consider the impact of the virus over the next year and advise on a plan to support social care services²⁸². With a membership drawn from all parts of the sector and supported by eight advisory groups, its final report noted that 54 of the 59 deliverable commitments in the government’s April social care action plan had been achieved. It went on to make 51 wide-ranging recommendations based on progress and learning from the first phase of the pandemic.

The taskforce proposed three key elements to increase the resilience of care services during the winter and beyond – the national offer (PPE, national testing, financial support); regional (agencies at this level ensuring they can assure the effectiveness, capability and risk mitigation in local systems) and local (all agencies working together to ensure there are winter plans to meet the needs of their local population that resilient and give confidence to the public²⁸³.

The work of the taskforce led to the publication in September of a Winter Plan for social care setting out the key elements of national support available for the social care sector and the actions to be taken by local authorities, NHS organisations, and social care providers, including in the voluntary and community sector. Its purpose is to “ensure that high-quality, safe and timely care is provided to everyone who needs it, whilst protecting people who need care, their carers and the social care workforce from COVID-19.”²⁸⁴ The Winter Plan continues many of the measures already set out in the existing social care action plan and care home support package, It commits a further £546m to extend the infection control fund for care providers to March 2021. A new hospital discharge policy and operating model procedures are being introduced to support safe and timely discharge²⁸⁵. From 1 September 2020 to 31 March 2021, the government has agreed to fund, via the NHS, the cost of post-discharge recovery and support services, such as rehabilitation and reablement, for up to a maximum of 6 weeks, in all settings.

²⁸¹ <https://www.nuffieldtrust.org.uk/research/how-will-brexit-affect-the-uk-s-response-to-coronavirus>

²⁸²

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/895133/The_Social_Care_Sector_COVID-19_Support_Taskforce_terms_of_reference.pdf

²⁸³ <https://www.gov.uk/government/publications/social-care-sector-covid-19-support-taskforce-report-on-first-phase-of-covid-19-pandemic/social-care-sector-covid-19-support-taskforce-final-report-advice-and-recommendations>

²⁸⁴ <https://www.gov.uk/government/publications/adult-social-care-coronavirus-covid-19-winter-plan-2020-to-2021/adult-social-care-our-covid-19-winter-plan-2020-to-2021#our-plan-for-adult-social-care-this-winter>

²⁸⁵ <https://www.gov.uk/government/publications/hospital-discharge-service-policy-and-operating-model>

A new policy is being introduced requiring local authorities to identify designated ‘safe places’ to which hospital patients testing positive for Covid-19 could be safely discharged²⁸⁶. This is likely to be controversial and difficult to implement given heightened concerns about hospital discharge during the pandemic and the risks associated with discharging people with positive Covid-19 status²⁸⁷. Rising levels of infection and hospitalisation will place greater pressure on hospital capacity so discharge is likely to remain a critical flashpoint.

A contentious area has been continuing restrictions on the ability of care home residents to receive visits. Evidence considered by SAGE suggests that visits have low impact on transmission and deaths but there is “substantial social and emotional impact on residents and, for end of life patients in particular, relatives.”²⁸⁸ Concerns about the impact of visiting restrictions on the mental wellbeing of residents and their human rights have led one charity to take legal action to challenge the government’s current guidance²⁸⁹.

In its annual assessment of the state of health and social care in England published in October, the Care Quality Commission - the independent regulator of health and care services) noted that the pandemic had thrown into stark relief longstanding problems in social care and urged that “the legacy of COVID-19 must be the recognition that issues around funding, staffing and operational support need to be tackled now – not at some point in the future”²⁹⁰.

The Government has reiterated its commitment to produce a plan for reforming social care and in January 2020 the Prime Minister stated that the Government would bring forward a plan “this year” and would “get it done within this Parliament”²⁹¹. But a government minister has recently stated there will be no plan before the end of 2020²⁹².

8. Short and longer term calls for action

8.1. Short-term priorities

- A single data portal for social care should be established, with timely data on the characteristics of people who use services and care providers and the impact of the pandemic.
- It is essential to support care providers in the implementation of measures, for those to be effective.

²⁸⁶ <https://www.gov.uk/government/publications/designated-premises-scheme-letter-to-directors-of-adult-social-services/winter-discharges-designated-settings>

²⁸⁷ <https://www.healthwatch.co.uk/report/2020-10-27/590-peoples-stories-leaving-hospital-during-covid-19>;
<https://www.amnesty.org.uk/files/2020-10/Care%20Homes%20Report.pdf?kd5Z8eWzi8Q6ryzHkcaUnxfCtqe5Ddg6=>

²⁸⁸

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/925856/S0770_NPIs_table_pivot.pdf

²⁸⁹ <https://www.bbc.co.uk/news/uk-54007273>

²⁹⁰ https://www.cqc.org.uk/sites/default/files/20201016_stateofcare1920_fullreport.pdf

²⁹¹ <https://www.bbc.co.uk/iplayer/episode/p080cg6r/the-big-interviews-boris-johnson-on-bbc-breakfast>

²⁹² <https://hansard.parliament.uk/lords/2020-09-15/debates/A97D2379-244A-477F-8510-62F078C97ED2/Covid-19NHSLong-TermPlan>

- At the operational and logistical levels, there needs to be a much more joined-up and sustainable approach to the implementation of guidance. This would need to cover procurement of PPE; encouragement of local approaches to testing and tracing that take full account of long-term care facilities, including domiciliary care and supported living schemes, and support for care homes that require additional space to implement isolation or cohorting. Both measures will be vital in keeping transmission of the virus as low as possible.
- There should be adequate financial support for adults using social care, unpaid carers and providers to meet the additional costs arising from reduced income and higher costs of staffing and PPE, thus helping to ensure their financial viability and continuity of care for people needing support.
- Efforts to enable family and other visitors to care homes need to be prioritised and supported through access to testing.
- As the NHS moves towards reinstating services suspended during the crisis, the needs of adults using social care should be given particular attention in terms of access to primary care, district nursing and other community health services; and for care home residents ensuring that recently agreed changes to the Enhanced Health in Care Homes Framework are fully implemented²⁹³.
- Increased pressure on social care staff needs to be addressed, as well as ensuring that they have access to adequate PPE, routine testing, full income while self-isolating, and relevant training.

8.2. Longer term policy implications

- COVID-19 has laid bare the fragmentation of organisational structures and responsibilities across the NHS and social care system, both at local and national levels²⁹⁴. This has left the care sector in the margins of planning and preparations despite the recognised inter-dependency between hospitals and care homes. Future arrangements to plan and manage further outbreaks, or future pandemics, should ensure that the needs of care homes and home care are considered in parallel with hospitals.
- COVID-19 has also highlighted the invisibility of working age adults in social care policy and planning, including the majority of adults with intellectual disabilities and autistic people living in places other than care homes. A management and operational plan for disabled people, as has been developed in Australia²⁹⁵, is required to generate focused attention and action.
- Existing arrangements to develop integration of health and social care services through sustainability and transformation partnerships and emerging integrating care systems need to be strengthened to ensure that the care sector is considered as an equal partner in whole system planning.
- The Government should ensure that policy decisions and guidance draw on advice and expertise in the areas of long-term care, social care, geriatrics, gerontology, physical disability, intellectual disability and autism.

²⁹³ <https://www.england.nhs.uk/wp-content/uploads/2020/03/the-framework-for-enhanced-health-in-care-homes-v2-0.pdf>

²⁹⁴ <https://www.kingsfund.org.uk/publications/covid-19-magnified-social-care-problems>

²⁹⁵ <https://www.health.gov.au/resources/publications/management-and-operational-plan-for-people-with-disability>

- COVID-19 has also exposed weaknesses in how data about the level of infection in care homes and other places where adults using social care live is identified, collected and used. This reflects longstanding deficiencies in data about the social care system in England²⁹⁶, especially the gap in data about people who fund their own care and informal carers. Producers of social care statistics should work together to secure better data that is more timely, comprehensive and accessible. Particular consideration should be given to establishing a single data portal for care homes²⁹⁷.
- The crisis has highlighted systemic weaknesses in the wider social care system including funding and workforce pressures²⁹⁸. Successive governments over the last three decades have failed to reform social care so that it can meet the needs of growing numbers of older people and working age people with care and support needs. A decade of austerity and severe cuts to local government funding has produced rising levels of unmet need and a fragile provider market that is struggling to deliver financially sustainable services. Action is also needed to develop a long-term plan for the workforce, that is lacking parity of esteem with health care professions despite growing acuity of needs²⁹⁹. Establishing a programme of long-term reform that addresses all of these challenges must now be a priority.

²⁹⁶ UK Statistics Authority Report on Adult Social Care Statistics in England

<https://www.statisticsauthority.gov.uk/publication/report-on-adult-social-care-statistics-in-england/>

²⁹⁷

https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&cad=rja&uact=8&ved=2ahUKewi06MHHI_LpAhXJQkEAHZDHBQQQfAAegQIAhAB&url=https%3A%2F%2Fwww.nihr.ac.uk%2Fnews%2Fnew-study-aiming-to-enhance-care-home-residents-quality-of-life-launched%2F22778&usg=AOvVaw0FNYpfjQ-OjMqODuj7qMQK

²⁹⁸ <https://www.kingsfund.org.uk/publications/covid-19-magnified-social-care-problems>

²⁹⁹ in line with the People's Plan for health, as has recently been announced in Wales: <https://heiw.nhs.wales/files/workforce-strategy-for-consultation/>