

AS IF EXPENDABLE

THE UK GOVERNMENT'S FAILURE TO PROTECT OLDER PEOPLE IN CARE HOMES DURING THE COVID-19 PANDEMIC



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Cover photo: An older woman looks out of a window during the Covid-19 pandemic, United Kingdom,16 April 2020. Stock Photo © EYESITE/Alamy



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GLOSSARY / Abbreviations

ADASS	Association of Directors of Adults Social Services
BMA	British Medical Association
CCG	Clinical Commissioning Groups
COVID-19	Coronavirus (SARS-CoV-2)
CQC	Care Quality Commission
DHSC	Department of Health and Social Care
DNAR	Do Not Attempt Resuscitation
DOLS	Deprivation of Liberty Safeguards
ECHR	European Convention on Human Rights
ESF	Emergency Support Framework
GMS	General Medical Services
GP	General Practitioner
ICESCR	International Covenant on Economic, Social and Cultural Rights
NHS	National Health Service
ONS	Office for National Statistics
PHE	Public Health England
PPE	Personal Protective Equipment
RCGP	Royal College of General Practice
WHO	World Health Organization

1. EXECUTIVE SUMMARY

"Our response to COVID-19 must respect the rights and dignity of older people."

UN Secretary General António Guterres.¹

Between 2 March and 12 June 2020, 18,562 residents of care homes in England died with COVID-19, including 18,168 people aged 65 and over, representing almost 40% of all deaths involving COVID-19 in England during this period.² Of these deaths, 13,844 (76%) happened in care homes themselves; nearly all of the remainder occurred in a hospital.³ During the same period, 28,186 "excess deaths" were recorded in care homes in England, representing a 46% increase compared with the same period in previous years.⁴ These excess deaths likely include undiagnosed COVID-19 deaths, and underscore the broader impact of the pandemic on older people in care homes.⁵

COVID-19 is an infectious respiratory disease caused by a coronavirus (SARS-CoV-2) first identified in China in December 2019. The earliest cases of COVID-19 in England were confirmed on 31 January 2020. The previous day, out of concern for the disease, the National Health Service (NHS) declared a Level 4 National Incident, the highest level of emergency.

The UK government, national agencies, and local-level bodies have taken decisions and adopted policies during the COVID-19 pandemic that have directly violated the human rights of older residents of care homes in England—notably their right to life, their right to health, and their right to non-discrimination.⁶ These decisions and policies have also impacted the rights of care home residents to private and family life, and

⁴ Ibid, Table 1.

¹ UNDESA Secretary-General's Policy Brief: The Impact of COVID-19 on older persons, 1 May 2020 (www.un.org/development/desa/ageing/news/2020/05/covid-19-older-persons/).

² Data set: Table 1 'Number of deaths of care home residents by date of death (ONS) and date of notification (CQC and CIW), from 28 December 2019 to 12 June 2020, registered up to 20 June 2020' in Office of National Statistics (ONS) 'Deaths involving Covid-19 in the care sector, England and Wales', 3 July 2020

www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglanda ndwales/deathsoccurringupto12june2020andregisteredupto20june2020provisional/relateddata and ONS 'Weekly provisional figures on deaths registered where coronavirus (COVID-19) was mentioned on the death certificate in England and Wales' in 'Deaths registered weekly in England and Wales, provisional 2020'. Accessed on 20/09/2020

www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/weeklyprovisionalfiguresondeathsregisteredine nglandandwales showing 45,739 deaths in England involving COVID-19 between 2 March and 12 June 2020. ³ ONS 'Deaths involving Covid-19 in the care sector, England and Wales' data, Table 6.

⁵ Of those care home residents in England and Wales whose death involved COVID-19, 49.5% had dementia. In addition, a higher proportion of deaths involving COVID-19 were reported among male care home residents than female care home residents across all age groups, although more females died of COVID-19 in care home (ONS). A higher proportion of deaths involving COVID-19 in care homes in England were also reported among Black people (54%) and Asian people (49%) compared to 44% of deaths of White people and 41% for mixed or multiple ethnic groups https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-care-settings-broken-down-ethnicity. It should be noted, as well, that in addition to care home residents, care home workers have been badly impacted by the disease. Social care workers (not all of whom work in care homes) have died from COVID-19 at more than double the rate of the general working population. ⁶ See the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Cruel, Inhuman or Degrading Treatment or Punishment, and the Convention on the Rights of Persons with Disabilities.

may have violated their right not to be subjected to inhuman or degrading treatment.

The UK government has known from the outset that COVID-19 presents a disproportionate risk of serious illness and death to older people, especially those with underlying health conditions.⁷ Risk of death estimates made in early March showed infection fatality rates ranging from 0.01% for people under 20 to 8% for people over 80.⁸

The UK government was clearly aware that the 400,000 residents of care homes in the UK, many of whom live with multiple health conditions, physical dependency, dementia and frailty, were at exceptional risk to coronavirus.⁹ Yet at the height of the pandemic, despite this knowledge, it failed to take measures to promptly and adequately protect care homes. Contrary to the claim by the secretary of state for Health and Social Care that a "protective ring" was put around care homes "right from the start," a number of decisions and policies adopted by authorities at the national and local level in England increased care home residents' risk of exposure to the virus—violating their rights to life, to health, and to non-discrimination. These include, notably:

- Mass discharges from hospital into care homes of patients infected or possibly infected with COVID-19 and advice that "[n]egative tests are not required prior to transfers / admissions into the care home".
- Advice to care homes that "no personal protective equipment (PPE) is required if the worker and the resident are not symptomatic," and a failure to ensure adequate provisions of PPE to care homes.
- A failure to assess care homes' capability to cope with and isolate infected or possibly infected patients discharged from hospitals, and failure to put in place adequate emergency mechanisms to help care homes respond to additional needs and diminished resources.
- A failure to ensure regular testing of care home workers and residents.
- Imposition of blanket Do Not Attempt Resuscitation (DNAR) orders on residents of many care homes around the country and restrictions on residents' access to hospital.
- Suspension of regular oversight procedures for care homes by the statutory regulating body, the Care Quality Commission (CQC), and the Local Government and Social Care Ombudsman.

Some of the UK government's decisions with regard to care homes seem heedless at best. Up until 13 March 2020, two days after the World Health Organization (WHO) declared COVID-19 a global pandemic, and despite having received information warning of asymptomatic coronavirus cases from its own advisers,¹⁰ the government advised care homes against the use of PPE. Its official guidance for care homes stated: "If neither the care worker nor the individual receiving care and support is symptomatic then no personal protective equipment is required above and beyond normal good hygiene practices."¹¹

Other government decisions appear inexplicable. Via its Department of Health and Social Care (DHSC), the government in mid-March adopted a policy, executed by NHS England and NHS Improvement, that led to 25,000 patients, including those infected or possibly infected with COVID-19 who had not been tested, being discharged from hospital into care homes between 17 March and 15 April—exponentially increasing the risk of transmission to the very population most at risk of severe illness and death from the disease. With no access to testing, severe shortages of PPE, insufficient staff, and limited guidance, care homes were overwhelmed. Although care home deaths were not even being counted in daily official figures of COVID-19 deaths until 29 April, some 4,300 care home deaths were reported in a single fortnight during this period.¹²

⁷ UK Government , 'SPI-M-O: Consensus Statement on 2019 Novel Coronavirus (2019-nCoV)," 3 February 2020, www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/887353/15-spi-m-o-consensus-statement-03022020.pdf.

⁸ UK Government, "SPI-M-O: Consensus Statement on 2019 Novel Coronavirus (COVID-19)," 2 March 2020,

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/887541/01-spi-m-o-consensus-statement-on-2019-novel-coronavirus-_COVID-19_.pdf.

¹⁰ Scientific Advisory Group for Emergencies (SAGE), "Influenza vs COVID planning assumptions," 10 February 2020,

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/887388/16-nsra-pandemic-influenzaplanning-assumptions-comparison-10022020.pdf.

⁹ British Geriatric Society, "Managing the COVID19 pandemic in care homes," 2 June 2020, <u>www.bgs.org.uk/resources/COVID-19-</u> managing-the-COVID-19-pandemic-in-care-homes.

¹¹ UK Government, COVID-19: Residential and supported living and home care, <u>www.gov.uk/government/publications/COVID-19-residential-care-supported-living-and-home-care-guidance</u>.

¹² See Robert Booth, "Care home fatalities to be included in daily coronavirus death tolls," *The Guardian*, 28 April 2020 <u>https://www.theguardian.com/world/2020/apr/28/uk-records-4343-care-home-coronavirus-deaths-in-a-fortnight</u>, and "COVID-19 in care homes in England: transparency statement," Office for National Statistics, 28 April 2020,

On 2 April, the same day that the WHO confirmed evidence of pre-symptomatic cases of coronavirus, the government reiterated its guidance for hospital discharges, stating that "negative tests are not required prior to transfers / admissions into the care home". Whereas the NHS was promised "whatever it needs, whatever it costs" to deal with the coronavirus outbreak, care homes were left to struggle to find PPE and cope with dramatically increased workloads and diminished staff capacity.¹³

A care home manager from Norfolk told Amnesty International about the situation she faced during this period:

[In March] we tried to order PPE ... We were getting in touch with our usual suppliers, but they were saying "we can't give them to you, they're on order for the NHS" ... We couldn't get hold of [PPE] for love or money.

Older care home residents were denied equal access to the NHS, as at times hospitals refused to admit care home residents, and many general practitioners (GPs) across the country stopped visiting care homes, having been advised to conduct remote consultations, although care home managers and staff, and families across the country expressed concern that often GPs did not come even in cases where it may have been clinically necessary to be present. Moreover, in several cases doctors asked that care homes include DNAR forms in all residents' files, without due process, while some care home staff interpreted DNARs to mean that residents should not be sent to hospital.

The daughter of a care home resident in Lancashire told Amnesty International:

The nurse from the GP surgery rang me up to say they decided mum is DNR (do not attempt resuscitation). I asked why and they said: "we did this across the home", and I said "no, this should be done on individual cases and I don't agree to it."

Similarly, a care home manager in Hampshire recalled:

There wasn't much option to send people to hospital. We managed to send one patient to hospital because the nurse was very firm and insisted that the lady was too uncomfortable ... In hospital the lady tested COVID positive and was treated and survived and came back. She is 92 and in great shape.

It was not until 15 April, by which time care homes were already suffering the peak of the outbreak, that the first COVID-19 action plan for the care sector was published and a policy of testing those discharged from hospitals was announced.¹⁴ But care homes were continuing to struggle to obtain sufficient PPE, while their access to testing remained severely limited.

As one care home manager from Hampshire recounted to Amnesty International:

We got our first tests on 13 April, but just three. We had about eight or 10 residents with symptoms but were told we could not get any more tests. They said "you just test three residents and if any of them are positive you should treat all the others as if they have COVID and isolate them."

The government's care home support package, aimed at reducing transmission of COVID-19 in care homes and backed by the Infection Control Fund, was not published until 15 May, while a Social Care Sector COVID-19 Support Taskforce to tackle and control the transmission of the virus was not established until June, when the rest of the country was coming out of lockdown. The roll-out of regular testing for care homes—which had been called for urgently by the sector and experts since the beginning of the pandemic—was not announced until 3 July and did not actually take place everywhere. Later in July the government recognized there were delays and promised to "reach all care homes" by 7 September-in other words, 220 days after the first COVID-19 cases were confirmed in England, and 221 days after the NHS declared a Level 4 National Incident.15

https://www.ons.gov.uk/news/statementsandletters/publicationofstatisticsondeathsinvolvingcovid19incarehomesinenglandtransparencystate

ment. ¹³ Care homes were not mentioned in the Treasury "Budget Speech 2020" of 11 March 2020, <u>www.gov.uk/government/speeches/budget-</u> speech-2020

¹⁴ ONS, Deaths involving Covid19 in care homes in England and Wales,

www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglanda ndwales/deathsoccurringupto12june2020andregisteredupto20june2020provisional

¹⁵ DHSC, 'Further information on coronavirus testing in care homes/Letter, 31 July 2020.

http://www.careengland.org.uk/sites/careengland/files/DHSC%20Care%20Home%20Testing%20-%20Letter%2031%20July%202020.pdf

Another important contributing factor was the suspension of the oversight mechanism for care homes at the outbreak of the pandemic in March—just as visits by families and others were suspended.¹⁶ By barring both oversight and family visits, the government increased the risk that care home residents would be exposed to abuses that would not be identified, reported and investigated.

A relative of a care home resident in Leeds described the lack of monitoring:

My mum is deteriorating so fast and she does not look well looked after at all. Whenever I try to engage with the management I get nowhere. I have contacted the CQC, the local authorities, everyone, but I have received no response. Nobody is going in [to the care home], so there are no witnesses to whatever is going on.

As the level of COVID-19 transmission decreased dramatically over the summer and visits recommenced in some form, the striking impact of the pandemic on the health and wellbeing of older people who survived in care homes has also become more visible. The consequences are tragic in some older people: reduced movement and cognitive functions, loss of appetite, depression, and a general loss of the will and desire to live. Certain disproportionate restrictions on the freedom of movement and association of care home residents must be urgently addressed, while remaining cognizant of social distancing and other infection control requirements.

It is imperative that the UK government—and in particular DHSC—reform its policies immediately, and take concrete measures to investigate what went wrong, hold accountable those responsible, and learn the necessary lessons. It must put in place mechanisms to avoid any recurrence of these problems, and to ensure that going forward the rights and dignity of older people are placed front and centre of decisions and policies relating to COVID-19 and future pandemics. It must also lift certain disproportionate restrictions that currently impede care home residents from exercising their rights to receive visits and meaningfully interact with the outside world.

A full independent public inquiry must be established without further delay, with urgent priority given to the commencement of an immediate interim phase to:

- Expeditiously produce all relevant records, policies, documents, minutes and other material retained by institutions, organisations and officials.
- Summon witnesses to give evidence under oath as to decisions and actions taken, and their reasoning and appropriateness.
- Make key recommendations on an urgent and expedited basis—by the end of November 2020.

At the same time, the relevant authorities must work with the care home sector and civil society to ensure that the issues already identified are addressed,¹⁷ ensuring notably:

- Equal access for care home residents, staff, and visitors to regular testing.
- Adequate representation and involvement of the social care and care home sector in the decisionmaking processes related to matters which impact care home residents at all levels.
- Adequate and continued supply of PPE for care homes to enable them to comply with national guidance and ensure all staff have undertaken training on its purpose and correct use.
- Adequate mechanism to assess and build the capacity of care homes to deliver appropriate infection prevention and control, including in regard to their ability to isolate new or returning residents effectively and limiting the movement of staff as much as possible between care homes; and to provide adequate care for residents with COVID-19 and other residents.
- Full access for care home residents to the NHS services to which they are entitled.
- A thorough review of DNAR forms that have been added to care home residents' care plans and medical files since the beginning of the pandemic to ensure they have been completed with the full knowledge, consideration and consultation of the resident and/or their family or independent

¹⁶ The suspension of visits by family and friends, also extended to visits from hairdressers, chiropodists and others.

¹⁷ The Government Adult social care COVID-19 winter plan 2020 2021' (<u>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</u>), published on 18 September, includes provisions which address some aspects these recommendations, depending on how they will be implemented.

advocate where they do not have mental capacity, according to the terms set out in the Mental Capacity Act. Ensure all staff working in the home understand when and how DNARs apply and that they do not in themselves indicate that a patient does not want to be taken to hospital or does not want to receive (non-CPR) medical treatment.

- Empowerment of care homes to develop visiting policies which respect and fulfil residents' human rights and which give voice and agency to them, their families, and/or their legal guardian, while ensuring their safety and that of their fellow residents.
- Full transparency in the collection and publication of all relevant data related to the deaths of older people in care homes during the COVID-19 pandemic.

2. METHODOLOGY

This report examines the impact of decisions, policies, and decision-making processes at the national and local level on the human rights of older people in care homes in England in the context of the COVID-19 pandemic. Research for this report was carried out between June and September 2020. Amnesty International interviewed 18 relatives of older people who either died in care homes or are currently living in care homes in different parts of England; nine owners, managers and staff of care homes in different parts of the country; eight staff and volunteers working in non-profit organisations advocating on behalf of care home residents and staff; three members of parliament and local authorities, and four legal and medical professionals. Special thanks go to relatives of current and deceased care home residents who shared their stories.

Most interviewees requested that their and their relatives' names and other details be withheld. Relatives of care home residents feared that publicity could make their relatives' situation worse, or that sympathetic carers who reported abuse to them might lose their jobs. Care home managers, staff, and volunteers feared that publicity could jeopardise their relations with their employers and with the local authorities.

Amnesty International decided not to interview care home residents themselves. Given the impossibility of conducting in-person interviews due to restrictions on care home visits, the organisation was concerned that remote interviews might, in the current circumstances, cause undue distress to interviewees who had been largely cut off from family and friends for several months.

Amnesty International requested data and information from the relevant government authorities (the Department of Health and Social Care, NHS England and NHS Improvement, Public Health England) and from the Care Quality Commission (CQC) on 4 August 2020, with follow up requests made on 25 August. Only NHS England and NHS Improvement and the CQC had responded by the time of publication. Their responses, however, only referred to publicly-available information and statements, and did not provide additional data beyond that which was already publicly available.

This report does not aim to address all the possible impacts of COVID-19 on care homes. More research is needed to explore possible concerns, including, notably, the impact on care home workers and on Black, Asian and Minority Ethnic care home workers and residents. Office of National Statistics (not disaggregated between care homes workers and other social workers) show a high death toll among social care workers,¹⁸ and according to a CQC report among COVID-19 related deaths of care homes residents a higher proportion were of Black and Asian people—54 and 49 percent, respectively—than of White people or people of mixed or multiple ethnic groups—44 and 41 percent, respectively.¹⁹

¹⁸ 'Deaths involving the coronavirus (COVID-19) among health and social care workers in England and Wales, deaths registered between 9 March and 20 July 2020', ONS,

 $[\]label{eq:https://www.ons.gov.uk/people population and community/health and social care/causes of death/adhocs/12112 deaths involving the coronavirus convict of the social carework of the social carework$

¹⁹ 'CQC publishes data on deaths in care settings broken down by ethnicity', CQC, 17 June 2020, https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-care-settings-broken-down-ethnicity

3. BACKGROUND

GOVERNANCE AND ACCOUNTABILITY

The structure of the health and social care system in England is complex, with multiple and overlapping lines of accountability with regard to individual care home residents' health and wellbeing.²⁰

At the national level, the Secretary of State for the Department of Health and Social Care (DHSC) has ultimate responsibility for protecting the population's health. The Secretary of State also has responsibility for oversight of the <u>National Health Service (NHS)</u> delivery and performance, oversight of health and social care policy, and an explicit duty to reduce inequalities in respect to the benefits of the health service.²¹

<u>NHS England and NHS Improvement</u> and <u>Clinical Commissioning Groups</u> (CCG) are responsible for the delivery of universal primary, community and hospital services, including those provided by general practitioners (GPs).²² The NHS also commissions some social care, including beds in care homes.²³

<u>Public Health England</u> is an executive agency of the Secretary of State and has responsibility for preparing for and responding to public health emergencies. It operates at local level through <u>Health Protection Teams</u> (HTPs) that work with the NHS, local authorities and other agencies.²⁴

Local authorities have a range of statutory duties in regard to social care under the Care Act 2014,²⁵ including commissioning services, providing information and advice, promoting effective operation of the social care market, and safeguarding adults at risk of abuse or neglect due to their care needs.²⁶ When commissioning a service, they have a duty to promote a person's well-being. Local authorities also have specific duties related to public health.²⁷ The Ministry of Housing, Communities and Local Government has responsibility for local government finance, which includes certain social care services, and the accountability system.²⁸

Care homes sit within this larger structure. There are two main types of care homes: residential homes, which provide accommodation and care for people who require support to look after themselves, and nursing homes, which provide accommodation and nursing care and assistance for residents who require care and supervision by a registered nurse.²⁹ Some care homes offer both residential and nursing care

https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance²⁷ House of Commons Library (2012) 'Local authorities' public health responsibilities (England)' 13 March 2014. www.commonslibrary.parliament.uk/research-

¹⁰ www.commonstandary.panametric.edu/research
 ²⁸ https://www.gov.uk/government/organisations/ministry-of-housing-communities-and-local-government

²⁰ What is social care and how does it work? <u>https://www.kingsfund.org.uk/projects/what-is-social-care</u>
²¹ UK Public General Acts (2012) Health and Social Care Act 2012. Accessed on 29.8.20

atwww.legislation.gov.uk/ukpga/2012/7/section/10

²² NHS England and NHS Improvement website: <u>www.improvement.nhs.uk/</u>

²³ NHS can commission beds in care homes during a discharge process or as part of NHS Continuing Healthcare and nursing care services for some care home residents.

²⁴ On the 18 August 2020 the Government announced the new National Institute for Health Protection 'to start work immediately', bringing together Public Health England (PHE) and NHS Test and Trace, as well as the Joint Biosecurity Centre (JBC) under a single leadership team. www.gov.uk/government/news/government-creates-new-national-institute-for-health-protection

²⁵ Care Act 2014, Factsheet <u>https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets</u>

²⁶ UK Public General Acts (2012) Health and Social Care Act 2012. <u>www.legislation.gov.uk/ukpga/2012/7/section/10 and Care Act 2014</u>. Department of Health and Social Care (2020) 'Care and support statutory guidance: Updated 24 June 2020',

²⁹ 'Understanding the different types of care home' <u>https://www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/care-homes/</u>

places. Private companies own and run 84% of beds in care homes for older people, while 13% of beds are provided by the voluntary sector and 3% by local authorities.³⁰ Care home places can be funded by local authorities, the NHS or privately. Around 41% of residents in care homes fund themselves (self-funders).³¹

The <u>Care Quality Commission</u> (CQC) is the body responsible for monitoring, inspecting and regulating care homes, to ensure they meet fundamental standards of quality and safety. A set of specific regulations apply to care homes, outlined <u>here</u>.³² When the CQC identifies failings in care homes, it has the power to issue warnings, make changes to care providers' registration, place providers in special measures (subjecting them to close supervision while working with other organisations to help them improve within set timescales), issue cautions or fines, and prosecute cases where people are harmed or placed in danger of harm.³³

The <u>Local Government and Social Care Ombudsman</u> can investigate individual complaints about adult care services, including in care homes.

The <u>National Institute for Health and Care Excellence</u> (NICE) and the <u>Social Care Institute for Excellence</u> (SCIE) both provide guidance on good practice while <u>Skills for Care</u>, an independent charity, is a delivery partner to DHSC tasked with adult social care workforce development.

Various structures for planning and commissioning health and care services exist at the local level, including <u>Health and Wellbeing Boards</u>, <u>Sustainability and Transformation Partnerships</u> (STPs) and <u>Integrated Care</u> <u>Systems</u> (ICSs). A range of <u>new models of care</u> have also emerged in recent years, including the <u>Enhanced</u> <u>Health in Care Homes</u> vanguard which seeks to improve access of care home residents to key service. Local <u>Primary Care Networks</u> including community, mental health, social care, pharmacy, hospital and voluntary services support the delivery of this new model of care.

During the coronavirus pandemic, <u>local resilience forums</u> (LRFs), multi-agency partnerships made up of representatives from local public services, including health and social care, have had responsibility for working together to plan and respond to localised incidents and emergencies.³⁴

LONG-TERM CHALLENGES FACING THE SOCIAL CARE SECTOR

The impact of COVID-19 on social care has been shaped—in part—by the underlying structure of the social care system. Measures to support care homes and other services have been implemented in the context of a system scarred by decades of political and policy neglect.

The Health Foundation, 29 July 2020.35

Care homes have been hit hard over the years by UK government austerity measures, and cuts have continued even recently. Spending per person on adult social care fell by some 12% in real terms between 2010/11 and 2018/19,³⁶ while the number of older people in England who were estimated to have an unmet need for social care had grown to 1.5 million by 2019.³⁷ Unmet need places significant pressure on England's 5.4 million informal care givers, many of whom provide over 50 hours of care per week.³⁸

www.health.org.uk/publications/reports/adult-social-care-and-COVID-19-assessing-the-policy-response-in-england ³⁶ Health Foundation (2020) 'The Health Foundation's response to the Health and Social Care Select Committee inquiry on social care: funding and workforce. Accessed on 29.08.20 at www.health.org.uk/sites/default/

files/2020-06/Health-Foundation-submission-to-HSC-social-care-funding-and-workforce-inquiry.pdf.

³⁷ 'The number of older people with some unmet need for care now stands at 1.5 million', Age UK, 9 November 2019 <u>https://www.ageuk.org.uk/latest-press/articles/2019/november/the-number-of-older-people-with-some-unmet-need-for-care-now-stands-at-1.5-million/</u>

³⁰ Some care homes may have a combination of beds – those supported by the private, voluntary, and public sectors. Many care homes are completely private sector supported and others are run by the voluntary sector or the local authorities. Also see: Blakeley, G and Quilter-Pinner, H (2019) 'Who Cares? Financialisation in Social Care'. IPPR. Accessed on 29.08.20 at www.ippr.org/files/2019-09/who-cares-financialisation-in-social-care-2-.pdf

³¹ Competition and Market Authority (CMA) (2017) 'Care homes market study: summary of final report'. Published 30 November 2017. <u>www.gov.uk/government/publications/care-homes-market-study-summary-of-final-report/care-homes-market-study-summary-of-final-report</u> ³² In addition to the CQC, the Competition and Markets Authority/Trading Standards also has powers to bring forward enforcement action if care homes are not meeting their obligations under the Consumer Law. Healthwatch England established by the Health and Social Care Act 2012, also exists as an independent consumer champion, for health and social care

³³ <u>https://www.cqc.org.uk/what-we-do/how-we-do-our-job/taking-action</u>

³⁴ These agencies are 'Category 1 Responders', as defined by the Civil Contingencies Act.

³⁵ Dunn, P, Allen, L, Humphries, R, Alderwick, H (2020) 'Briefing: Adult social care and COVID-19:

Assessing the policy response in England so far'. The Health Foundation, 29 July 2020. Accessed on 29.08.20 at

³⁸ 'Fact and figures', Carers UK, <u>https://www.carersuk.org/news-and-campaigns/press-releases/facts-and-figures#:~:text=1%20in%208%20adults%20(around,women%20and%2042%25%20are%20men&text=As%20of%202019%20there%20</u>

Concerns have been raised in recent years about "persistent downwards pressure on the quality and adequacy of care provided to older people", 39 including neglect in care homes. 40

There is significant market fragility in the care sector, with a rising number of providers going out of business or handing back contracts, and the risk of market collapse.⁴¹ In some areas of England, the model has already broken down completely and "is no longer capable of delivering care to people in need."⁴² Local authorities also typically pay less for somebody's care in a care home than what it costs to provide it, leading to self-funders "cross-subsidising low fees paid by local authorities."43

According to Skills for Care, an organisation that supports adult social care employers to deliver what the people they support need, the sector lacks a workforce strategy and out of a total of 1.49 million people working in adult social care, 440,000—or one-third—leave their job each year.⁴⁴ Before the COVID-19 pandemic hit, there were almost 120,000 vacancies; 24% of staff were recorded as casual workers employed on zero hours contracts,⁴⁵ and rising numbers were being paid at or close to the National Living Wage.⁴⁶ There is also a limited learning and development offer in the sector leading to gaps in the skill-set required to care for people with rising levels of need.⁴⁷

Whereas NHS services are provided free at the point of delivery on the basis of UK residency and delivered through a single organisational structure, social care services are both means and needs assessed, with significant local variation in access and performance.⁴⁸ There were 18,500 organisations involved in providing or organizing adult social care in the sector in 2018,49 with 5,500 different providers operating 11,300 care homes for older people.⁵⁰

Poor integration of the health and social care services are reported at both organisation and delivery level,⁵¹ and despite significant action to address this, multiple issues have hampered progress on delivering holistic, person-centred care for service users.⁵² One of the implications is that, despite the average care home resident having multiple long-term conditions and often complex care needs requiring support from a range of health and care services, they often face barriers in accessing universal NHS services that they have a right to.53

Social care also faces data challenges. The Office for Statistics Regulation has reported that the sector is "very poorly served by data", and that "a scarcity of funding has led to under investment in data and analysis, making it harder for individuals and organisations to make informed decisions."⁵⁴

The lack of prioritisation of social care on the political and policy agenda was reflected in cross-government pandemic preparations prior to COVID-19. Professor Martin Green, chief executive of Care England, a representative body for independent care providers, recently argued that key social care recommendations

44 Skills for Care (2019) 'State of the adult social care sector'. Accessed on 29.08.20 at www.skillsforcare.org.uk/adult-social-care-workforcedata/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/State-of-Report-2019.pdf ⁵ https://www.gov.uk/contract-types-and-employer-responsibilities/zero-hour-contracts

- www.health.org.uk/publications/long-reads/health-and-social-care-workforce
- ³ Bottery, S (2019)

49 Skills for Care (2019) www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/docuents/State-of-the-adult-socialcare-sector/State-of-Report-2019.pdf

50 CMA (2017)

- ⁵² Ibid, Chapter 7. Disjointed care: delayed transfers of care and lack of integration with health
- ⁵³ NHS England (2016) 'The Framework for enhanced health in care homes'. Accessed on 29.08.20 at www.england.nhs.uk/wpcontent/uploads/2016/09/ehch-framework-v2.pdf ⁵⁴ Office for Statistics Regulation (2020) 'Adult social care statistics in England', p. 3. Accessed on 29.08.20 at

could,adult%20carers%20in%20the%20UK and Ipsos Mori (2017) Unmet need for care - Final Report. www.ipsos.com/si s/default/files/2017-07/unmet-need-for-care-full-report.pdf

³⁹ Age UK 2017

www.kingsfund.org.uk/publications/whats-your-problem-social-care#workforce⁴¹ Ibid. ⁴⁰ Bottery, S (2019) 'What's your problem, social care? The eight key areas for reform'. Web article. The King's Fund.

⁴² Incisive Health (2019) Care deserts: the impact of a dysfunctional market in adult social care provision. Age UK. www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/care--support/care-deserts---age-ukreport.pdf

⁴³ Dunn, P, Allen, L, Humphries, R, Alderwick, H (2020) 'Briefing: Adult social care and COVID-19: Assessing the policy response in England so far'. The Health Foundation, 29th July 2020. www.health.org.uk/publications/reports/adult-social-care-and-covid-19-assessingthe-policy-response-in-england; National Audit Office (2020) 'Readying the NHS and adult social care in England for COVID-19'. June 12 2020. www.nao.org.uk/report/readying-the-nhs-and-adult-social-care-in-england-for-covid-19/

⁴⁶ Ibid, p. 21

⁴⁷ Health Foundation, 'Health and social care workforce: Priorities for the new government'. November 2019.

⁵¹ Ibid., Chapter 8. The postcode lottery: unwarranted variation in access and performance

www.osr.statisticsauthority.gov.uk/publication/report-on-adult-social-care-statistics-in-england/

following Exercise Cygnus, a simulation exercise carried out by NHS England in October 2016 to estimate the impact of a hypothetical H2N2 influenza pandemic,⁵⁵ were not implemented, even though the National Risk Register of Civil Emergencies published by the Cabinet Office in 2007 said that a new flu strain pandemic could potentially lead to between 20,000 and 750,000 fatalities.⁵⁶ He explained: "[T]here was no recognition in either the planning process that happened in 2016 or, indeed, at the very start of the current pandemic that the people most at risk were in care homes, so we should have prioritised care homes both in the planning that went on for 2016 and in the planning that went on at the very start of this pandemic."⁵⁷ This was despite the fact that after Exercise Cygnus, the National Risk Register of Civil Emergencies stated: "It is difficult to forecast the spread and impact of a new flu strain or disease until it starts circulating. However, consequences may include: for pandemic flu: up to 50% of the UK population experiencing symptoms."⁵⁸

⁵⁵ 'What was Exercise Cygnus and what did it find?' The Guardian, 7 May 2020 <u>https://www.theguardian.com/world/2020/may/07/what-was-exercise-cygnus-and-what-did-it-find</u>

⁵⁶ National Risk Register Of Civil Emergencies, 2017 edition

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/644968/UK_National_Risk_Register_201 7.pdf ⁵⁷ House of Commons (2020) 'Health and Social Care Committee Oral evidence: Management of the Coronavirus Outbreak, HC 36'.

 ⁵⁷ House of Commons (2020) 'Health and Social Care Committee Oral evidence: Management of the Coronavirus Outbreak, HC 36 Tuesday 19 May 2020, Question 477. Accessed on 29.08.20 at <u>www.committees.parliament.uk/oralevidence/407/html/</u>
 ⁵⁸ National Risk Register Of Civil Emergencies, 2017 edition, page 34,

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/644968/UK_National_Risk_Register_201 7.pdf

4. THE GOVERNMENT RESPONSE TO THE COVID-19 PANDEMIC

Despite knowledge of the increased risk of COVID-19 to older people, the UK government failed in several areas to take appropriate action to try to protect care home residents from the disease. A number of poor decisions at both the national and local levels had serious negative consequences for the health and lives of older people in care homes, and resulted in the infringement of their human rights.

A CHRONOLOGY OF FAILURE

The first case of COVID-19 in England was confirmed by the Chief Medical Officer, Chris Whitty, on 31 January 2020,⁵⁹ a day after the NHS declared a Level 4 National Incident.⁶⁰

On 3 February 2020, the government's Scientific Pandemic Influenza Group on Modelling (SPI-M) prepared a consensus statement on COVID-19 highlighting risk factors associated with fatality, including "an individual's age and co-morbidities."⁶¹ On 3 March 2020, the government's Coronavirus Action Plan emphasised: "So far the data we have suggest that the risk of severe disease and death increases among elderly people and in people with underlying health risk conditions (in the same way as for seasonal flu)."⁶²

On 2 March 2020, in an updated consensus statement, SPI-M stated, "It is highly likely that there is sustained transmission of COVID-19 in the UK at present. It is almost certain that there will be sustained transmission in the UK in the coming weeks."⁶³ The paper stated the best estimate of COVID-19's infection fatality rate was "0.01% for the under-20s, but was 8% for those aged over 80."⁶⁴ Yet despite this information, Public Health England (PHE) guidance published on 25 February, which remained in place until 13 March 2020, maintained that "there is currently no transmission of COVID-19 in the community" and that it was "very unlikely that anyone receiving care in a care home or the community will become

- ⁶¹ UK Government, 'SPI-M-O: Consensus Statement on 2019 Novel Coronavirus (2019-nCoV)," 3 February 2020,
- www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/887353/15-spi-m-o-consensus-statement-03022020.pdf. The SPI-M gives expert advice to the Department of Health and Social Care and wider UK government (see https://www.gov.uk/government/groups/scientific-pandemic-influenza-subgroup-on-modelling).

⁵⁹ UK Department of Health and Social Care (DHSC), "CMO confirms cases of coronavirus in England," 31 January 2020, www.gov.uk/government/news/cmo-confirms-cases-of-coronavirus-in-england.

⁶⁰ National Audit Office, "Readying the NHS and adult social care in England for COVID-19," 2020, p. 15, <u>https://www.nao.org.uk/wp-content/uploads/2020/06/Readying-the-NHS-and-adult-social-care-in-England-for-COVID-19.pdf</u>.

⁶² DHSC (2020) 'Policy paper: Coronavirus action plan: a guide to what you can expect across the UK'. Published 3 March 2020.

https://www.gov.uk/government/publications/coronavirus-action-plan/coronavirus-action-plan-a-guide-to-what-you-can-expect-across-the-uk ⁶³ DHSC (2020) 'SPI-M-0: Consensus statement on 2019 novel coronavirus (COVID-19), 2 March 2020', p.

https://www.gov.uk/government/publications/spi-m-o-consensus-statement-on-2019-novel-coronavirus-covid-19-2-march-2020 ⁶⁴ Ibid.

infected." It advised that "[t]here is no need to do anything differently in any care setting at present."65

On 11 March 2020, the World Health Organization (WHO) declared COVID-19 to be a pandemic. WHO Director-General Tedros Ghebreyesus stated: "We cannot say this loudly enough, or clearly enough, or often enough: all countries can still change the course of this pandemic. If countries detect, test, treat, isolate, trace, and mobilize their people in the response." The next day, 12 March 2020, the UK government announced it was halting community testing.⁶⁶ The decision went against WHO advice, which has consistently maintained that testing is the backbone of the pandemic response: "But we have not seen an urgent enough escalation in testing, isolation and contact tracing ... We have a simple message for all countries: test, test, test."67

On 13 March, PHE guidelines for care homes were provided for the first time.⁶⁸ By this point, the government's Scientific Advisory Group for Emergencies (SAGE) had concluded that "[a]symptomatic transmission cannot be ruled out and transmission from mildly symptomatic individuals is likely,"69 and asymptomatic cases of COVID-19 among passengers evacuated from Hubei Province were already being reported in the media.⁷⁰ Yet the PHE's guidance advised staff to use personal protective equipment (PPE) only with residents displaying COVID-19 symptoms. It specifically stated: "If neither the care worker nor the individual receiving care and support is symptomatic then no personal protective equipment is required above and beyond normal good hygiene practices."71

The 13 March guidance also included advice for care homes to "review" visiting policies, for residents displaying symptoms of COVID-19 to be isolated in their rooms, and for care homes to "[w]ork with local authorities to establish plans for mutual aid, including sharing of the workforce between providers."⁷² The latter advice is of particular concern as movement of staff between care homes was found by a study commissioned by the DHSC to increase the risk of transmission of COVID-19,73 especially at the time when there was no regular testing of care home staff. Most care homes imposed a lockdown on or shortly after 13 March, though some care home managers told Amnesty International that they did so earlier on their own initiative. As one care home owner in the north of England explained, "we were seeing on the news what was happening in Italy and in the absence of government guidelines, we decided to lock down at the end of February."

The government also informed providers that a single and one-off 'free issue of PPE to support adult social care providers to support compliance with the updated advice' was to be issued by the government and that "Arrangements will be put in place for adult social care providers to access further PPE as necessary".⁷⁴ A cross-government plan to "ensure that PPE is delivered to NHS and care staff" was not announced until 10 April,⁷⁵ by which time the rates of COVID-19 infections and deaths were fast approaching their peaks.⁷⁶

https://www.who.int/dg/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---16-march-2020 ⁶⁸ March 13 Guidance, https://www.gov.uk/government/publications/COVID-19-residential-care-supported-living-and-home-care-guidance 69 'Influenza vs COVID planning assumptions, SAGE, 10 February 2020.

www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/887388/16-nsra-pandemic-influenzaplanning-assumptions-comparison-10022020.pdf

'Coronavirus patients can have similar "viral load" whether or not they show symptoms', CNN, 19 February 2020 https://edition.cnn.com/asia/live-news/coronavirus-outbreak-02-19-20-intl-hnk/index.html

⁷² DHSC (2020) Official Statistics: Vivaldi 1: COVID-19 care homes study report <u>www.gov.uk/government/publications/vivaldi-1-coronavirus-</u> COVID-19-care-homesstudy-report/vivaldi-1-COVID-19-care-homes-study-report

⁶⁵Public Health England (PHE) (2020) 'Guidance for social or community care and residential settings on COVID-19' Published 25 February 2020, Chapter 18. 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

⁶⁶Parliament UK (2020) 'Coronavirus: Screening: Written question – 30157' www.parliament.uk/written-questions-answersstatements/written-question/commons/2020-03-16/30157 ⁶⁷ WHO Director-General's opening remarks at the media briefing on COVID-19 - 16 March 2020,

⁷¹ PPE such as gloves and aprons are generally worn in care when administering personal care and hygiene or providing meals but not during other interactions with residents, including physical contact such as holding hands or hugging, which is especially common for patients with dementia, who make up a significant percentage of care home residents.

⁷³ The Vivaldi study (commissioned by the DHSC with the aims to measure the prevalence of COVID-19 in care homes and the use of disease control measures in each setting) showed higher virus levels among staff, particularly those working temporarily in multiple care settings. https://www.ons.gov.uk/releases/impactofcoronavirusincarehomesinenglandvivaldi26mayto19june2020 ⁷⁴ PHE 'COVID-19: guidance for supported living and home care'. First published on 13 March 2020.

www.gov.uk/government/publications/covid-19-residential-care-supported-living-and-home-care-guidance . In normal circumstances Care Homes are responsible for procuring their own PPE but that was no longer possible in the context of he pandemic, because of the much greater quantities of PPE required and increased difficulties of finding PPE on the market, with suppliers prioritizing NHS requirements DHSC 'Coronavirus (COVID-19): Personal Protective Equipment (PPE) Plan Published. 10 April 2020

https://www.gov.uk/government/collections/coronavirus-covid-19-personal-protective-equipment-ppe

⁶https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredweeklyinenglandand walesprovisional/weekending10april2020

Problems accessing sufficient PPE to match changing guidelines continued after this, according to care home workers interviewed by Amnesty International and to public reports.⁷⁷

A full UK lockdown was announced by the prime minister on 23 March 2020, but it was not until 15 April that the government's "COVID-19: adult social care action plan" was published. Plans to support infection control and prevention in care homes were not announced until 15 May—by which time 5,176 care home residents had died with COVID-19.⁷⁸

Regular testing for care home staff and residents—which had been urgently called for by the sector since March,⁷⁹ and which is considered by experts as the most crucial protection measure against transmission in general,⁸⁰ and against transmission in care homes in particular⁸¹—was not announced until July 2020, and has yet to be fully achieved, according to care home staff and managers.⁸²

Some experts compared the government's response to protecting care homes to the greater priority given to protecting that NHS. The Health Foundation, for example, emphasised that "[p]rotecting and strengthening social care services appears to have been given far lower priority by national policymakers than protecting the NHS."⁸³ Similarly, Baroness Ros Altmann, a member of the House of Lords and former pension minister, said: "[c]are homes were left behind in the scramble for PPE, for emergency admission, ventilation and for testing ... It's almost as if the system is stacked against them."⁸⁴

In contrast to measures taken to boost NHS capacity, care home managers and staff told Amnesty International of a "complete breakdown" of systems in care homes in the first six weeks of the pandemic. They spoke of waiting to receive guidance, of struggling to access adequate amounts of PPE, and of having no access to testing, despite having to manage patients urgently discharged from hospitals, including those infected with COVID-19. These deficits put many of those most vulnerable to the virus at great risk—as well as endangering care home staff—and, in doing so, violated care home residents' right to life, right to health, and right to non-discrimination.

A care home owner in the north of England, recalled that period:

We suddenly stopped having contact with managers at the local authority and were asked to go through a commissioning email box. We didn't have any contact with Local Resilience Forums, Health Protection Teams, we were just fighting on the front line. We were left out there alone without any tangible support.

A volunteer at a charity-run care home told Amnesty International: "My manager sent an email to Adult Social Care [the department of the local Council responsible for adult social care services] and received a one-line reply saying, 'This is a role for commissioning, managers in the home are the ones with responsibility'. I was there with managers and staff doing everything they could."

Giving evidence to the Parliament's Health and Social Care Select Committee, Professor Martin Green, head

⁷⁷ https://www.theguardian.com/world/2020/may/09/uk-care-homes-scramble-to-buy-their-own-ppe-as-national-deliveries-fail
⁷⁸ ONS 'Deaths involving Covid19 in care homes in England and Wales', Table 6: Number of deaths involving COVID-19 of care home
residents by place of death, occurring from 2 March 2020 to 12 June 2020.
www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglanda
ndwales/deathsoccurringupto12june2020andregisteredupto20june2020provisional
⁷⁹ 'Care homes demand urgent coronavirus testing and equipment as outbreaks affect residents', The Telegraph, 24 March
2020 https://www.telegraph.co.uk/news/2020/03/24/care-homes-demand-urgent-coronavirus-testing-equipment-outbreaks/
⁸⁰ "We have a simple message for all countries: test, test, test, Dr Tedros Adhanom Ghebreyesus, WHO Director General, 16 March 2020
https://www.bbc.co.uk/news/av/world-51916707
⁸¹ https://www.carehomeprofessional.com/breaking-news-regular-testing-announced-for-care-home-staff-and-residents/
⁸² Health and Social Care Committee Oral evidence: Preparations for coronavirus, HC 36. 26 March 2020
www.committees.parliament.uk/oralevidence/268/default/. DHSC letter, 'Further information on coronavirus testing in care homes', dated
31 July 2020. www.careengland.org.uk/sites/careengland/files/DHSC%20Care%20Home%20Testing%20-
%20Letter%2031%20July%202020.pdf . 'Covid-19 test results for care home nurses 'consistently delayed and lost', Nursing Times, 15
September 2020 https://www.nursingtimes.net/news/coronavirus/covid-19-test-results-for-care-home-nurses-consistently-delayed-and-lost-
15-09-2020/. 'Care home bosses claim government is failing on coronavirus tests', The Times, 15 September 2020
https://www.thetimes.co.uk/article/care-home-bosses-claim-government-is-failing-on-coronavirus-tests-rpdv26f9w
⁸³ Health Foundation (2020) 'Assessing the impact of COVID-19 on social care users and staff in England',
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 . Also see 'What does the 2020 spring Budget mean for health and care?', The King's Fund, 13 March 2020
https://www.kingsfund.org.uk/blog/2020/03/spring-budget-mean-health-and-care
⁸⁴ 'The elderly in care homes are being abandoned like lambs to the slaughter', The Daily Mail, 13 April 2020
https://www.dailymail.co.uk/debate/article-8215507/Fx-Health-Secretary-elderly-care-homes-abandoned-like-lambs-slaughter.html and

https://www.dailymail.co.uk/debate/article-8215507/Ex-Health-Secretary-elderly-care-homes-abandoned-like-lambs-slaughter.html and 'Coronavirus: Baroness Altmann says health system is 'stacked against' care homes'; BBC, 14 April 2020 https://www.bbc.co.uk/news/av/uk-52281684 of Care England, the organization which represents care homes, said pandemic planning had been completely inadequate and the government had focused on the NHS while discharging infected patients into care homes: "Given that the care homes are full of people with underlying health conditions, we should have looked at focusing on where the people at most risk were, rather than thinking about particular organisations."85

A care home manager in the south of England recalled: "Our local hospital always had over 500 empty beds and so staff were not under pressure and they had lots of PPE. We had 45 percent of the staff self-isolating and were scrambling to get PPE and even food. The special slots for NHS shoppers [at the local supermarket] did not apply to care home staff. We should have had some support from community nurses, if only NHS and Social Care was better integrated."

The sections below delineate the government's key errors in failing to protect care home residents.

DISCHARGE OF PATIENTS FROM HOSPITALS INTO CARE HOMES

On 17 March 2020 NHS England announced the decision to urgently discharge patients, including those who were infected or who may have been infected with COVID-19, from hospitals into care homes and the community. This was among the most crucial decisions that adversely affected care homes across the country.

The Coronavirus Act set down before Parliament the same week included measures to ensure that the assessment of patients' eligibility to social care funding did not delay discharge; additional funding was also made available to support the process.⁸⁶ Neither the letter with instructions sent to NHS providers nor the Discharge Requirements that followed on 19 March stipulated that patients should be tested on leaving hospital or upon entering a care home.⁸⁷ No risk assessment that might have been carried out on these plans has been published or discussed publicly, or even with care home managers interviewed by Amnesty International whose institutions received patients from hospital. No action appears to have been taken in advance to assess the capacity of care homes to care for patients with COVID-19, their ability to isolate such patients safely and manage infection prevention and control (IPC), or to ensure that, at a minimum, they had sufficient amounts of PPE.⁸⁸ Further guidance on "Admission and Care of Patients during COVID-19," published on 2 April, stated explicitly: "Negative tests are not required prior to transfers / admissions into the care home."89

According to the National Audit Office, this policy lead to 25,000 people being sent untested from hospitals into care homes between 17 March and 25 April, putting at risk the health and indeed the lives of care home residents.⁹⁰ The DHSC did not collect data on the extent to which care homes successfully isolated residents with confirmed or suspected COVID-19 and did not require local authorities to collect data either.⁹¹

Several care home managers told Amnesty International that they had no COVID-19 cases in their care homes until after the received patients who were discharged from hospital. A care home owner and manager

⁸⁵ House of Commons Health and Social Care Select Committee hearing, 19 May 2020.

www.committees.parliament.uk/oralevidence/407/pdf/

⁸⁶ Measures included delaying NHS Continuing Healthcare Assessments for individuals on the acute hospital discharge pathway and in community settings until the end of the COVID-19 emergency period. Changes also meant patients would not be able to wait in hospital until their first choice of care home has a vacancy, meaning a short spell in an alternative care home until patients were able to move to their preferred long-term care home. £.3bn was also allocated to the NHS to help discharge patients from hospitals, including to pay for the care and support they may need from social care services. See UK Government 'COVID-19 Hospital Discharge Service Requirements'. 19 March 2020 assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/911541/COVID-19 hospital discharge service requirements 2.pdf

https://www.england.nhs.uk/coronavirus/publication/covid-19-hospital-discharge-service-requirements/

⁸⁸ Amnesty International asked the relevant government authorities (the Secretary of State for Health and Social Care, the Chief Executive of Public Health England, and the Medical Director of NHS England and NHS Improvement for information about any such measures taken to assess and support capacity of care homes to manage intake of residents infected/possibly infected with COVID-19. Only the Medical Director of NHS England and NHS Improvement responded, but failed to provide any information about these issues, except for reiterating that "The DHSC did not collect data on the extent to which care homes successfully isolated staff with confirmed or suspected COVID-19 and did not require local authorities to collect data either" (Letter from Professor Stephen Powis, dated 8 September). ⁸⁹ UK Government (2020); Admission and Care of Patients during Covid19' First published 2 April 2020.

www.gov.uk/government/publications/coronavirus-covid-19-admission-and-care-of-people-in-care-homes/coronavirus-covid-19-admissionand-care-of-people-in-care-homes

⁹⁰ National Audit Office (2020) 'Readying the NHS and adult social care in England for COVID-19', p. 15. https://www.nao.org.uk/wpcontent/uploads/2020/06/Readying-the-NHS-and-adult-social-care-in-England-for-COVID-19.pdf ⁹¹ Ibid, page 47

in Yorkshire explained: "Because of what we'd witnessed in Spain and Italy, we stopped visitors on 28 February and got PPE. We had no cases until 28 March when a resident was discharged from hospital with COVID."

Similarly, a care home manager in northern England told Amnesty International: "We've had COVID-19 in the care home—two cases—one death in the home and one death in the hospital. In our opinion both came from individuals going into NHS facilities and coming back."

A care home volunteer told Amnesty International: "I think the reason [our] home was hit so late and protected for so long was because we were full. There was no space for people being discharged from hospital."

In a survey of care home nurses carried out between March and May 2020 by the Queen's Nursing Institute, 21% (31) said their home took people discharged from hospital with COVID-19 and 43% (70) said their home accepted people whose status was unknown.⁹²

The discharge of thousands of patients from hospitals to care homes in the days following 17 March was extremely rushed, leaving little or no time for consultations and assessments. "We had 500-600 empty beds and nobody coming into A & E so there really was no need for such rushed discharges," a member of a discharge team at a hospital in the south of England told Amnesty International. A care home manager recalled: "Families learned their relatives came to care homes on the spot. There was no time for them to discuss with hospitals or with us. Families had no chance to choose which care home, to visit the place, to meet us. People's teeth and glasses went missing in the rush."

A number of care home owners, managers and staff told Amnesty International that they argued with hospital discharge teams and ambulance staff dropping people off, because they were concerned that patients discharged from hospital without having been tested could spread the virus to residents and staff.

A member of a care homes management team recalled:

At times, after we had told the discharge team that we were not going to take in discharged patients other than our own residents, ambulances turned up in the evening once the manager had gone off and the duty deputy manager scrambled to contact the manager to check whether our policy had changed and we were supposed to take in people discharged from hospital. This happened more than once.

Another described negotiating the fate of residents:

With a 101-year old lady [who was a resident], [the hospital discharge team] said, "If you don't take her back, we'll get social services to take her to another care home." This is her home, she has been with us for several years; we did not want her to be sent to another place ... I contacted the MP and he contacted the local authority and the hospital agreed to take her back... and she recovered well and is back with us now.

A survey conducted by the Association of Directors of Adults Social Services (ADASS) in May found that 23% of directors thought more than half of care home infections were attributable to hospital discharges; 54% disagreed people were tested during the period of rapid discharge; 27% disagreed that they were discharged to providers that had sufficient PPE, and 24% disagreed people were discharged to settings where they could isolate safely.⁹³ Research by the Alzheimer's Society in May found that 58% (61) of 105 care homes said they did "not feel able to effectively isolate suspected COVID-19 residents" being discharged from hospital.⁹⁴ Astonishingly neither the government nor the CQC have shown any interest in understanding the impact and consequences of those urgent discharges from hospitals to care homes of infected or possibly infected patients. On the contrary, "the Department [DHSC] did not collect data on the extent to which care homes successfully isolated residents with confirmed or suspected COVID-19 and did not require local authorities to collect data either."⁹⁵

- ⁹² https://www.qni.org.uk/wp-content/uploads/2020/08/The-Experience-of-Care-Home-Staff-During-Covid-19.pdf
- ⁹³ Association of the Directors of Adult Social Services (ADASS) (2020) 'ADASS CORONAVIRUS SURVEY 2020', p. 15. www.adass.org.uk/media/7967/adass-coronavirus-survey-report-2020-no-embargo.pdf
- ³⁴ Alzehimer's Society, "Care homes 'left to fend for themselves' against coronavirus," 13 May 2020, <u>www.alzheimers.org.uk/news/2020-05-</u> 13/care-homes-left-fend-themselves-against-coronavirus.
- ⁵⁶ National Audit Office, 'Readying the NHS and adult social care in England for COVID-19," p. 47, <u>https://www.nao.org.uk/wp-</u>content/uploads/2020/06/Readying-the-NHS-and-adult-social-care-in-England-for-COVID-19.pdf.

Care home managers have reported to Amnesty International, as well as to the media, that they were pressured in different ways to accept patients discharged from hospital who had not been tested or who were COVID-19 positive.⁹⁶ Government guidance from 2 April stated that care homes needed to make their full capacity available."⁹⁷ Managers of care homes where local authorities had block-purchased beds in their facilities who were uncomfortable about accepting patients discharged from hospital felt that they had no choice but to honour their contractual obligation—even though the COVID-19 risk intervened after they had signed the contract. There have also been reports of financial pressure being put on homes to receive people with coronavirus, including care homes being offered cash to take people patients discharged from hospital,⁹⁸ and local authorities making additional funds conditional on care homes accepting patients discharged from hospital untested or COVID-19 positive.

Durham County Council – Making funding to care homes conditional on accepting patients from hospital

Amnesty International has received a number of reports and has seen documentary evidence that Durham County Council made funding for coronavirus-related costs conditional on care homes accepting patients discharged from hospital untested or COVID-19 positive.

On the 19th April, the government announced £1.6bn un-ringfenced funding for local authorities to support COVID-19-related costs. On the same day £1.3bn was also allocated to the NHS to help discharge patients from hospitals, including to pay for patients' stay in care home or other social care services. In allocating funding at local level, Durham County Council wrote to 98 local homes offering a 10% additional COVID-19 temporary funding to care homes who agreed to accept "new referrals; either from hospital discharge / community, or inclusive of people who have had a diagnosis of / are recovering from COVID-19."

A County Durham Council official told Amnesty International: "I was contacted by concerned residents, saying 'surely we wouldn't put COVID-19 patients in care homes where the most vulnerable are?' But commissioning [he council commissioning department] said, yes we are ... When I asked the council why, they told me that that they had projected figures of 1000s of hospital beds regionally needing to be available due to COVID-19 and that we needed to make sure the NHS wouldn't fall. But we had hospital bed capacity at that time and Sunderland NHS Nightingale [hospital] was 9 miles away."

A care home provide in County Durham told Amnesty International: "I sent a letter to the Council saying, 'What?' This money was offered without stipulations from [central] government."

In all, 10 care homes signed up to this contract to accept patients discharged from hospital, including those untested or infected with COVID-19. Some care home providers in the area challenged the Council, demanding an assessment of the extent to which care homes could safely provide care to people with the virus and ensure adequate infection prevention and control measures. They did not receive a response. Asked why some care homes signed up to the contract, one person told Amnesty International, "It was absolutely about funding. These are businesses and they would not have had full occupancy without accepting patients from hospital."

ONS data shows that there were 401 deaths of care home residents involving COVID-19 in County Durham between 6 March and 12 June 2020.⁹⁹ According to council data, just under 70 older residents had died from COVID-19 in the county's three worst-hit care homes by 29 July, including 27 at Sandringham, 23 at Melbury Court and 18 at Stanley Park, Stanley.¹⁰⁰ Two of these, Melbury Court and Stanley Park, are

https://news.sky.com/story/coronavirus-care-homes-faced-funding-cut-if-they-didnt-take-in-covid-19-patients-11986578. ⁹⁷ National Audit Office, "Readying the NHS and adult social care in England for COVID-19', p. 47. <u>https://www.nao.org.uk/wp-content/uploads/2020/06/Readying-the-NHS-and-adult-social-care-in-England-for-COVID-19.pdf</u>

⁹⁹ ONS, "Deaths involving COVID-19 in the care sector, England and Wales: Provisional counts of the number of deaths and agestandardised mortality rates involving the coronavirus (COVID-19) within the care sector occurring up to 12 June 2020 and registered up to 20 June 2020." 3 July 2020.

https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsinvolvingcovid19inthecaresectore nglandandwales. ¹⁰⁰ "Covid-19: County Durham care home 'recorded 27 deaths,'" BBC News, 29 July 2020, <u>https://www.bbc.com/news/uk-england-tees-</u>

¹⁰⁰ "Covid-19: County Durham care home 'recorded 27 deaths,'" BBC News, 29 July 2020, <u>https://www.bbc.com/news/uk-england-tees-53579462#:~:text=The%20deaths%20from%20Covid-19,Auckland%20died%20with%20the%20virus.</u>

⁹⁶ See, for example, "Sky News contacted a large cross-section of care homes in Britain. More than 90 responded. We asked: Did you feel pressure from hospitals to take patients before 15 April? 70% told us they did," Sky News, 12 May 2020,

 ⁹⁸ "Care homes offered cash to take coronavirus patients," *Telegraph*, 28 August 2020, <u>https://www.telegraph.co.uk/news/2020/08/28/care-homes-offered-cash-take-coronavirus-patients/.
 ⁹⁹ ONS, "Deaths involving COVID-19 in the care sector, England and Wales: Provisional counts of the number of deaths and age</u>

reported to have signed the contract, although Stanley Park reportedly disputes this.¹⁰¹

Jane Robinson, Corporate Director of Adult and Health Services at Durham County Council, was questioned on the issue during Country Durham's Corporate Overview and Scrutiny Management Board meeting on 19 June 2020. In both this session and in media reports on the issue, she has said that the council followed national guidelines.¹⁰² The issue was also raised in a House of Commons Public Accounts Committee hearing on 22 June 2020, when Rosamond Roughton, Director General of Adult Social Care at DHSC, was asked, "Was it ever the Government's guidance that more money should be given to those willing to accept patients from hospital who either had tested positive or were untested?" She replied that it was not.¹⁰³

Following the 15 April government guidance on testing patients before being discharged from hospital, the council wrote to care home providers on 24 April 2020 stating that they were amending the conditions related to the 10% additional funding and confirming that "providers will now not be required to accept new referrals; either from hospital discharge / community, or inclusive of people who have had a diagnosis of / are recovering from COVID-19, in order to receive the 10% uplift." Neither the names of the care homes who signed the original contract nor the number of COVID-19 deaths that occurred in those care home prior to the 24 April change in council policy has been provided by the council. Amnesty International wrote to Jane Robinson on 25 August 2020 seeking information and clarification about the case, but received no response.

It was not until 15 April—after the peak of coronavirus infections in care homes,¹⁰⁴ and eight days after WHO confirmed reports of pre-symptomatic transmission¹⁰⁵—that the government announced they would test all those discharged from hospital into care homes, giving the NHS responsibility for this.¹⁰⁶ The 15 April guidance also stated that "where a test result is still awaited, the patient will be discharged and pending the result, isolated in the same way as a COVID-positive patient will be."107 It added, "[i]f appropriate isolation/cohorted care is not available with a local care provider, the individual's local authority will be asked to secure alternative appropriate accommodation and care for the remainder of the required isolation period." On 19 June, additional guidance was added which, for the first time, explicitly stated that "No care home will be forced to admit an existing or new resident to the care home if they are unable to cope with the impact of the person's COVID-19 illness for the duration of the isolation period."108

However, a care home manager told Amnesty International in August that only days earlier he was still having to fight for a resident to be tested on discharge from hospital and, while the Government's new COVID-19 Winter Plan¹⁰⁹ partly addresses the need for assessing the capacity of care homes to safely isolate and provide care for residents with COVID-19, much will depend on implementation.

DENIAL OF ACCESS TO HOSPITALS AND OTHER MEDICAL SERVICES

Amnesty International has received multiple reports of care home residents' right to NHS services, including access to general medical services (GMS) and hospital admission, being denied during the pandemic, violating their right to health and potentially their right to life, as well as their right to non-discrimination. Care homes managers have pointed out that such reluctance or refusal to admit older care home residents to hospital could not be explained by need, as hospital bed capacity was never reached.¹¹⁰

¹⁰³ House of Commons Public Accounts Committee, Formal meeting (oral evidence session): Readying the NHS and social care for the COVID-19 peak, 22 June 2020, www.committees.parliament.uk/event/1295/formal-meeting-oral-evidence-session/. ¹⁰⁴ ONS 'Deaths involving Covid19 in care homes in England and Wales'.

www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglanda ndwales/deathsoccurringupto12june2020andregisteredupto20june2020provisional ¹⁰⁵ WHO COVID-19 Timeline, 2 April, <u>https://www.who.int/news-room/detail/29-06-2020-covidtimeline</u>

¹⁰⁶ DHSC, "COVID-19: our action plan for adult social care," www.gov.uk/government/publications/coronavirus-covid-19-adult-social-careaction-plan/covid-19-our-action-plan-for-adult-social-care.

¹⁰¹ Ibid.

¹⁰² "Coronavirus: Durham County Council accused of 'increasing' deaths,'" BBC News, 2 June 2020, <u>www.bbc.com/news/uk-england-tyne-</u> 52893853

¹⁰⁸ UK Government, "Admission and Care of Patients during COVID-19," first published 2 April 2020, updated on 19 June 2020, www.gov.uk/government/publications/coronavirus-covid-19-admission-and-care-of-people-in-care-homes/coronavirus-covid-19-admissionand-care-of-people-in-care-homes.

¹⁰⁹ Adult social care COVID-19 winter plan 2020 to 2021, 18 September 2020 https://www.gov.uk/government/publications/adult-socialcare-coronavirus-covid-19-winter-plan-2020-to-2021/adult-social-care-our-covid-19-winter-plan-2020-to-2021

¹¹⁰ "Why do so many NHS Nightingale hospitals remain empty?" Telegraph, 29 April 2020, https://www.telegraph.co.uk/news/0/do-many-

Care home managers and staff and relatives of care home residents in different parts of the country told Amnesty International how, in their experience, sending residents to hospital was discouraged or outright refused by hospitals, ambulance teams, and GPs. A manager in Yorkshire said: "We were heavily discouraged from sending residents to hospital. We talked about it in meetings; we were all aware of this."

Another manager in Hampshire recalled:

There wasn't much option to send people to hospital. We managed to send one patient to hospital because the nurse was very firm and insisted that the lady was too uncomfortable and we could not do any more to make her more comfortable but the hospital could. In hospital the lady tested COVID positive and was treated and survived and came back. She is 92 and in great shape.

She explained that:

There was a presumption that people in care homes would all die if they got COVID, which is wrong. It shows how little the government knows about the reality of care homes.

The son of one care home resident who passed away in Cumbria said that sending his father to hospital had not even been considered:

From day one, the care home was categoric it was probably COVID and he would die of it and he would not be taken to hospital. He only had a cough at that stage. He was only 76 and was in great shape physically. He loved to go out and it would not have been a problem for him to go to hospital. The care home called me and said he had symptoms, a bit of a cough and that doctor had assessed him over mobile phone and he would not be taken to hospital. Then I spoke to the GP later that day and said he would not be taken to hospital but would be given morphine if in pain. Later he collapsed on the floor in the bathroom and the care home called the paramedic who established that he had no injury and put him back to bed and told the carers not to call them back for any Covid-related symptoms because they would not return. He died a week later.

He was never tested. No doctor ever came to the care home. The GP assessed him over the phone. In an identical situation for someone living at home instead of in a care home, the advice was "go to hospital". The death certificate says pneumonia and COVID, but pneumonia was never mentioned to us.

The daughter of a care home resident in Leeds recalled: "My mum got COVID and recovered. She was not taken to hospital. I was not even asked; they [the care home] did not even speak to me about it. She has a DNR but that does not mean she shouldn't get the necessary care."

A care home manager in Yorkshire told Amnesty International:

In March, I tried to get [a resident] into hospital—the ambulance had employed a doctor to do triage but they said, "Well he's end of life anyway so we're not going to send an ambulance" ... Under normal circumstances he would have gone to hospital ... I think he was entitled to be admitted to hospital. These are individuals who have contributed to society all their lives and were denied the respect and dignity that you would give to a 42-year-old; they were [considered] expendable.

Eileen Chubb from Compassion in Care, a care workers whistle-blower group, said that a large number of care workers reported that they had found it difficult or impossible to secure hospital admission for care home residents.

The problem was widely reported early on in the pandemic,¹¹¹ and was seemingly exacerbated by guidelines published by NHS England on its website on 10 April advising that some care home residents "should not ordinarily be conveyed to hospital unless authorised by a senior colleague."¹¹² The guidelines caused a controversy and were withdrawn a few days later but the damage lingered. Hospitals, CCGs and GP surgeries

nhs-nightingale-hospitals-remain-empty/

¹¹¹ Mike Laycock, "Care home boss: hospitals refusing to admit residents with coronavirus," *York Press*, 5 April 2020, https://www.yorkpress.co.uk/news/18359376.care-home-boss-hospitals-refusing-admit-residents-coronavirus/; Katherine Rushton and Sophie Barnes, "Perfect storm in care homes as residents refused hospital treatment," *Telegraph*, 24 April 2020, https://www.telegraph.co.uk/news/2020/04/24/perfect-storm-care-homes-residents-refused-hospital-treatment/.
¹¹²"Prejudiced' hospital admissions guidance for the elderly dropped by NHSE', HSJ, 15 April 2020, https://www.tsi.co.uk/news/2020/04/24/perfect-storm-care-homes-residents-refused-nospital-treatment/.

from COVID-19, Britain left many of the weakest exposed," Reuters, 5 May 2020, <u>https://uk.reuters.com/article/uk-health-coronavirus-</u> britain-elderly-sp/special-report-in-shielding-its-hospitals-from-covid-19-britain-left-many-of-the-weakest-exposed-idUKKBN22H2EI.

continued to discourage or deny hospitalisation of care home residents, a perception developed among care home staff that hospitalisation was not generally an option.

With the problem seemingly persisting, the CQC felt it necessary to issue a statement in August 2020 addressing the issue. The statement stressed:

It is vitally important that older and disabled people living in care homes and in the community can access hospital care and treatment for COVID-19 and other conditions when they need it during the pandemic ... Providers should always work to prevent avoidable harm or death for all those they care for. Protocols, guidelines and triage systems should be based on equality of access to care and treatment. If they are based on assumptions that some groups are less entitled to care and treatment than others, this would be discriminatory. It would also potentially breach human rights, including the right to life, even if there were concerns that hospital or critical care capacity may be reached.¹¹³

Official figures show admissions to hospital for care home residents decreased substantially during the pandemic, with 11,800 fewer admissions during March and April compared to previous years.¹¹⁴ The Health Foundation has noted that while there may have been a number of reasons for reduced admissions, "the data suggest that there may be unmet need for health care among care home residents as a result of COVID-19."115 The Joint [Parliamentary] Committee on Human rights expressed concern that "decision-making relating to admission to hospital, in particular critical care, for adults with Covid-19 has discriminated against older and disabled people."116

Reduced possibility to send care homes residents to hospital compounded another long-standing issue, that of care homes residents' limited access to GPs.¹¹⁷ Obtaining access to GPs got markedly more challenging during the pandemic, as GPs throughout the country switched to phone/online consultations and stopped visiting care homes. NHS England advised GPs to begin the roll out of remote consultations on 17 March 2020, prioritising vulnerable groups but limiting face-to-face consultation to only "when absolutely necessary."¹¹⁸ However, guidance on 15 April stated that "end of life care, including palliative care, must continue to be planned in a holistic way involving social care, community nursing, general practice, occupational therapy, and others"-including "access in people's homes and care homes to professionals and equipment that support this."119 NHS England outlined a range of additional measures on 1 May to increase NHS primary care and community health support to care homes.¹²⁰ However, Amnesty International received multiple reports from care homes managers and staff and relatives of care home residents throughout the country of doctors refusing to enter care homes and only being available for consultations by phone or via video calls, no matter what the residents' symptoms were and even in regard to end of life support. Indeed this was the case for almost all the cases researched by the organization. Similarly, the Alzheimer's Society said in May 2020 that 79 out of 105 care homes it had surveyed had

¹¹⁹ https://www.gov.uk/government/publications/coronavirus-covid-19-adult-social-care-action-plan/covid-19-our-action-plan-for-adultsocial-care ¹²⁰ NHS England. Letter. NHS primary care and community health support to care homes. 1st May 2020

https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/COVID-19-response-primary-care-and-community-healthsupport-care-home-residents.pdf

¹¹³ Care Quality Commission, "Access to hospital care and treatment for older and disabled people living in care homes and in the community during the pandemic," 14 August 2020, https://www.cqc.org.uk/guidance-providers/adult-social-care/access-hospital-caretreatment-older-disabled-people-living. ¹¹⁴ Health Foundation, "Assessing the impact of Covid-19 on social care users and staff in England," p. 19,

https://www.health.org.uk/publications/reports/adult-social-care-and-covid-19-assessing-the-impact-on-social-care-users-and-staff-inengland-so-far. ¹¹⁵ "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 needs. During March and April, discharges from hospitals to residential care homes were 75% of the historical average, while discharges from hospitals to nursing homes increased to 120% of the historical average. These difficult decisions to discharge patients were made in an urgent and uncertain context but may have played a role in transferring risk to a poorly supported social care system". Ibid. ¹¹⁶ 'The Government's response to COVID-19: human rights implications', Joint Committee on Human Rights, House of Commons House of Lords, 21 September 2020, https://committees.parliament.uk/publications/2649/documents/26914/default/

¹¹⁷ 'GPs vote to withdraw healthcare services for elderly care home residents, Care Home Professional, 1 February 2016, https://www.carehomeprofessional.com/gps-vote-to-withdraw-healthcare-services-for-elderly-care-home-residents/; 'Fix Dementia Care -NHS and care homes, Alzheimer's Society, April 2016,

https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/fix_dementia_care_nhs_and_care_homes_report.pdf; "Care home residents 'denied basic GP medical services,'" BBC News, 11 March 2012, https://www.bbc.co.uk/news/health-17264349.

¹¹⁸ NHS England. Letter on Next Steps on NHS Response to COVID-19: shift to remote GP appointments and GP pay for performance framework suspended, 17 March 2020, www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/20200317-NHS-COVIDletter-FINAL.pdf

reported that "GPs have been reluctant to visit residents."121

A senior staff member in a care home group that owns a large number of care homes told Amnesty International:

It varied across the country, but GPs and district nurses have not come into the majority of our homes since the beginning of the pandemic. Not even to carry out essential work, like changing a catheter, which care workers cannot do. That was a huge problem. Some of the care staff were forced to carry out work which they should not do, but there was no choice. Luckily many of our managers are former nurses and carry out many of these tasks. But it was a huge problem, and still is a problem. Remote consultations are often inadequate, especially for residents who cannot describe their symptoms well and so doctors have to rely on [care home workers] carers, who have no medical training, to interpret the residents' symptoms and convey these to a doctor. At times a video call cannot replace a stethoscope.

The ADASS survey in May also raised concern that there were "insufficient primary and community services in their local areas to support local people's needs."¹²²

A care home owner in northern England said: "We have a great relationship with the GP team ... But when COVID started, a doctor came and said 'I can't come back to the care home. You can email and make calls.' I haven't had a doctor through the doors since." He added "We were always in touch with GPs before and then they point-blank refused to come and would do everything over the phone."

The daughter of a care home resident who died in Liverpool described the lack of medical care her father experienced:

In the file it says that dad complained of chest pain on 28 March and asked to see a doctor but there was no follow up in the file ... In the file it also says that dad had fallen on morning of 1 May and banged his head and had a swelling. I was never told and there is no record of a doctor being called for this. On 1 May a carer told me they had rang the doctor but the doctor was not going in [to the care home] and had prescribed antibiotic and end of life drugs. Then I spoke to the GP and he said he suspected COVID or chest infection and that I should go see him. Dad died on 2 May and a staff member told me she was there when dad died and he was gasping for breath and holding his chest.

As experts have pointed out, "[p]alliative care has an important role to play in the response to COVID-19, in order to ensure that people dying as a result of COVID-19—including care home residents—do so with dignity, with emotional support available and free of pain".¹²³ However, "[in care homes] there is typically no GP presence, no palliation, no fluids, no syringe drivers and no staff with end of life training."¹²⁴ If transferring residents to hospital is not possible and trained staff are not available, people at the end of their lives risk avoidable suffering and discomfort.

MISUSE OF 'DO NOT ATTEMPT RESUSCITATION' (DNAR) FORMS

Throughout the pandemic, concerns about the inappropriate use of Do Not Attempt Resuscitation (DNAR) forms have been repeatedly raised. A DNAR form (or DNACPR form, which stands for do not attempt cardiopulmonary resuscitation) is a document issued and signed by a doctor to inform a medical team not to attempt cardiopulmonary resuscitation (CPR). It is designed to communicate a patient's wishes to healthcare professionals involved in their care. DNARs may be included as part of an advanced care plan or be included independently in a patient's files.¹²⁵ Any decision regarding DNARs must be made on an individual

¹²⁵ An advance care plan records of a person's preferred place of care or death, decisions to refuse treatment, and lasting powers of attorney. For those lacking mental capacity, advance care plans are agreed with their families or advocates. See: 'An introduction to advance care planning in practice', British Medical Journal, 21 October 2013, <u>http://gsfcentre.co.uk/cd-content/uploads/files/ACP/An%20intro%20to%20advance%20care%20planning%20in%20practice.pdf</u>

¹²¹ 'Care homes 'left to fend for themselves' against coronavirus', Alzheimer's Society, 13 May 2020,

https://www.alzheimers.org.uk/news/2020-05-13/care-homes-left-fend-themselves-against-coronavirus

¹²² ADASS Coronavirus Survey, p. 10.

¹²³ Annette Bauer, Josie Dixon and Adelina Comas-Herrera 'End-of-life support for people in care homes in the context of COVID-19: international report'. LTC Covid. May 1, 2020. <u>www.ltccovid.org/2020/05/01/end-of-life-support-for-people-in-care-homes-in-the-context-of-covid-19-international-report/</u> ¹²⁴ Bob Hudson, Professor at the Centre for Health Services Studies, University of Kent. LSE Blog. May 14 2020 'A policy scandal of epic

¹²⁴ Bob Hudson, Professor at the Centre for Health Services Studies, University of Kent. LSE Blog. May 14 2020 'A policy scandal of epic proportions: Why a public inquiry into adult social care and COVID-19 is necessary'. <u>www.blogs.lse.ac.uk/politicsandpolicy/covid19-adult-</u> <u>social-care-inquiry/</u>

basis by the patient involved and/or their families where they have legal guardianship, ensuring they have the necessary information to make an informed decision.

The blanket imposition of DNACPR notices without proper patient involvement is unlawful. The evidence suggests that the use of them in the context of the Covid-19 pandemic has been widespread.¹²⁶

Concerns about blanket imposition of DNAR were reported across the country, pointing to flaws with how decisions were taken and policies communicated to those who are supposed to implement them—CCGs, GPs, and care homes. Care home managers reported to Amnesty International and to media cases of local GP surgeries or Clinical Commissioning Groups (CCGs) requesting them to insert DNAR forms into the files of residents as a blanket approach.¹²⁷

Asked about any blanket approaches to DNARs, one care home owner in the north of England told Amnesty International, "We had a letter to that effect from the practice. I refused to sign it and handle it like that." Another reported that they were asked to insert DNAR forms into a number of residents' files. A family from Lancashire told Amnesty International that their relatives had been asked to sign a DNAR form without having understood what it meant.

The nurse from the GP surgery rang me up to say they decided mum is DNR. I asked why and she said "we did this across the home", and I said "no, this should be done on individual cases and I don't agree to it". So I had it taken off ... She also said that they would not take mum to hospital and again I said that is something that would have to be decided if and when need arose on the basis of the situation at the time. They had asked mum about the DNR and she had agreed to it but then I spoke to mum and she had not really understood the issue.

Sussex - Blanket approaches to DNARs and "do not convey to hospital" decisions

A group of six Sussex CCGs, including Brighton and Hove CCG and East Sussex CCG issued guidance on 23 March 2020 for 'COVID-19 actions for all General Practices (GP) to follow in support of Care Homes'. The document, seen by Amnesty International, instructed all practices to "Search your clinical system for any care home patients who do not have a resuscitation order recorded (either 'not for' or 'for' resuscitation) and put appropriate orders in place' and to 'Ask the [care] home to check they have resuscitation orders on every resident". The guidance also included instructions related to hospital admission, asking GPs to ensure "patients who do not already have a 'do not convey to hospital' decision are prioritised and have one in place".

The guidance included a suggested script for use to "facilitate" these discussions with relatives and carers. It said: "Frail elderly people do not respond to the sort of intensive treatment required for the lung complications of coronavirus and indeed the risk of hospital admission may be to exacerbate pain and suffering. We may therefore recommend that in the event of coronavirus infection, hospital admission is undesirable."

The guidance was reportedly sent to 35 GP surgeries and in response 98 care homes were contacted about the above guidance, including being asked to put DNARs on the files of every patient. One senior local figure told Amnesty International of the distress that the guidance caused.

He explained: "Discussions on advanced care planning should be warm and natural conversations. This is not how they should be done. One care home with 26 residents had 16 residents sign DNARs in a 24-hour period. It was distressing for staff and residents ... Care homes felt like they were being turned into hospices, and being asked to prepare to manage deaths instead of managing life."

One care home manager in Hove reported being told "none of your residents aged over 75 will be admitted

¹²⁶ 'The Government's response to COVID-19: human rights implications', Joint Committee on Human Rights, House of Commons House of Lords, 21 September 2020, <u>https://committees.parliament.uk/publications/2649/documents/26914/default/</u>

¹²⁷ Among those who raised concerns about the imposition of DNARs without due process is the Advocacy charity PoHwer, which reported that "we have identified multiple examples of DNAR orders being inappropriately used and 'blanket' DNARs being applied by GPs to all residents in particular care homes without people being consulted with appropriately." 'POhWER's Response to Covid-19 Impact Report', 2020, <u>https://www.pohwer.net/Handlers/Download.ashx?IDMF=b5beeb94-df19-4b0b-9449-e97c578a3814</u>

to hospital" and feeling "shocked and numb" to hear that.128

The guidance from the CCG also indicated that GPs should conduct medical assessments remotely and that "visits will be rare". A senior figure at a local health organisation told Amnesty International that "GPs in the area decided they wouldn't visit homes."

Following investigations by a senior local figure and news coverage of the story, the CCG responded that while "agreeing advance care plans is a routine and important part of how GPs and care homes support their patients and residents, we recognise there may have been undue alarm caused by the interpretation of this particular guidance."¹²⁹ A local official told Amnesty International that the CCG sent a follow-up letter apologising and clarifying guidance shortly after the news coverage.

The Sussex case and others documented by Amnesty International and elsewhere, including in Derbyshire, Greater Manchester and Somerset,¹³⁰ indicate that pressure was being exerted from the acute sector to freeup hospital beds with little concern for the consequences on the health and lives of those in other settings, including care homes, or for equal treatment in access to care.

Discussing how the CCG guidance came to be issued, a senior local figure told Amnesty International that it was clear from conversations he had with senior figures in the local health system that they were under "an enormous amount of pressure from upwards" and that they were given instructions orally which were not sent in writing or would be worded differently when sent in writing. This would explain why so many CCGs and GPs asked care homes to put DNAR instructions on their residents in a blanket approach even though there is no written record of any such government policy.

The concern about blanket DNAR instructions was widespread and serious enough, right from the outset of the pandemic, to prompt warnings by the UK's main medical and social care bodies at the beginning of April 2020. In a joint statement issued on 1 April, the British Medical Association (BMA), the Royal College of General Practice (RCGP), the Care Quality Commission (CQC), and the Care Provider Alliance (CPA) warned that: "It is unacceptable for advance care plans, with or without DNAR form completion to be applied to groups of people of any description. These decisions must continue to be made on an individual basis according to need."¹³¹

This was followed on 7 April by a statement from NHS England and NHS Improvement:

[T]he key principle is that each person is an individual whose needs and preferences must be taken account of individually. By contrast blanket policies are inappropriate whether due to medical condition, disability, or age. This is particularly important in regard to "do not attempt cardiopulmonary resuscitation" (DNACPR) orders, which should only ever be made on an individual basis and in consultation with the individual or their family.¹³²

However no concrete action appears to have been taken since these statements to review the DNAR forms newly added to care home residents' medical files and to ensure the removal from residents' files of DNAR forms imposed without due process.

In at least one case a care home inspected by the CQC at the end of June 2020—that is, almost three months after the warnings issued by the BMA, CPA, CQC and RCGP and by NHS England—was found to have imposed blanket DNAR forms on all the residents. The CQC found that:

The registered manager and provider failed to recognise people's right to life, in line with Article 3 of the human rights act. Do not resuscitate forms had been implemented for all people living in the

¹³⁰ Sussex Express 'Concerns over do not resuscitate orders placed on East Sussex care home residents'. 28 April 2020 <u>www.sussexexpress.co.uk/health/concerns-over-do-not-resuscitate-orders-placed-east-sussex-care-home-residents-2552906</u> and BBC News 3rd April 2020.

¹²⁸ 'Coronavirus: Care workers 'shocked' by virus treatment guidance', BBC News, 3 April 2020. <u>https://www.bbc.com/news/uk-politics-52155359</u>

¹²⁹ Ibid.

¹³¹ Joint statement by the British Medical Association (BMA), the Care Provider Alliance (CPA), the Care Quality Commission (CQC) and the Royal College of General Practice (RCGP), 1 April 2020 <u>www.rcgp.org.uk/about-us/news/2020/april/joint-statement-on-advance-care-</u> planning.aspx

¹³² Letter, Ruth May, Chief Nursing Officer in England and Professor Stephen Powis, National Medical Director at NHS England and NHS Improvement, 7 April 2020. https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/maintaining-standards-quality-of-care-pressurised-circumstances-7-april-2020.pdf

home in light of Covid-19. Systems and processes failed to recognise the correct assessment process had not been followed. $^{\rm 133}$

A survey among 163 nurses and managers of nursing homes in May 2020 by the Queen's Nursing Institute found that 16 respondents reported "negative changes which they found challenging such as "blanket DNACPR" decisions, or decisions taken about resuscitation status by others (GPs, hospital staff or clinical commissioning groups) without discussion with residents, families or care home staff, or that they disagreed with some of the decisions on legal, professional or ethical grounds".¹³⁴

INADEQUATE ACCESS TO TESTING

My colleagues at the Crick contacted Downing Street in March and wrote to Minister Hancock in April, emphasising two main things. The first was the importance of regular, systematic testing of all healthcare workers, including not only frontline doctors and nurses but support staff, ambulance drivers, and other healthcare providers such as care homes, GP surgeries, community nurses and the like. They all needed to be tested.

Professor Sir Paul Nurse, chief executive and director, Francis Crick Institute, and winner of the 2001 Nobel Prize in Physiology or Medicine, 21 July 2020.¹³⁵

With healthcare workers you need to be testing in a mandatory way twice a week in order to pick up a sufficient number of asymptomatic cases.

Professor Sir Jeremy Farrar, director, Wellcome Trust, 21 July 2020.¹³⁶

[W]e absolutely have responsibility to protect care homes now. And we protect them by testing people and making sure we are not bringing infection into these really vulnerable communities.

Christina Pagel, director of the Clinical Operational Research Unit at University College, London, quoted in The Independent on 2 August 2020. $^{\rm 137}$

Why was my mum not tested sooner? Not taken to hospital sooner? Maybe she could have been saved

The daughter of a woman who died in a care home in the north of England told Amnesty International: "On 11 April Mum told me on the phone that she was hot. I rang the care home to ask if they could take her temperature. On 17 April, Mum was tired and had a runny nose and was generally unwell and the following day she developed a cough and a care practitioner told me that maybe she had hay fever and that another resident had the same symptoms. (I later learned from that resident's daughter that she had COVID, but she pulled through).

On 19 April she was very weak and was found on the floor unconscious with diarrhoea, and paramedic were called. On TV they had said [COVID-19] tests were available, so I asked for her to be tested. I called the regional manager who called 111 but was told that tests were not available. On 20 April the care home called the GP, who checked for tests and was told no test would be available until the following week.

On 21 April the nurse told me Mum was better. On 22 April the nurse again told me Mum was better. On 23 April I received an email update from the care home which said that there were no residents with symptoms of concerns—although Mum and at least one other resident did have symptoms. (In the meantime the manager had left and the deputy manager had taken over, but I later learned that within two days she was off with COVID.) On 27 April Mum improved but still had a cough.

On 1 May 5.30pm she called me and said she was in pain and had sore toes. She was confused; not herself. I called the care home and the nurse said she was poorly. On 2 May she was found on the floor with a

 ¹³³ Everley Residential Home Inspection report, CQC, 7 August 2020 <u>https://api.cqc.org.uk/public/v1/reports/03ba067e-1540-4b4b-87e9-31ec581a6a69</u>
 ¹³⁴ Survey, The Queen's Nursing Institute (QNI), 24 August 2020, <u>https://www.qni.org.uk/news-and-events/news/major-new-survey-of-care-</u>

 ¹³⁴ Survey, The Queen's Nursing Institute (QNI), 24 August 2020, <u>https://www.qni.org.uk/news-and-events/news/major-new-survey-of-care-home-leaders-confirms-severe-impact-of-covid-19/</u>
 ¹³⁵ House of Commons Health and Social Care Select Committee hearing, 19 May 2020. Q568.

https://committees.parliament.uk/oralevidence/747/pdf/

¹³⁶ Ibid.

¹³⁷ Andrew Woodcock, "Coronavirus: Ministers accused of 'negligence' towards care home residents and staff," *Independent*, 2 August 2020, https://www.independent.co.uk/news/uk/politics/coronavirus-care-home-negligence-residents-staff-stats-testing-a9650176.html.

temperature. A 111 doctor came and said Mum had a chest infection and gave her antibiotic, but she still was not tested. On 3 May I called and Mum was very poorly. On 4 May the nurse said mum was better but depressed. On 5 May I spoke to Mum and she was crying. On 6 May I called Mum and she could not speak much. On 7 May I was told Mum was now incontinent and I had to buy diapers. A nurse told us that Mum was tested on 5 May but we never received the results. A carer said mum was deteriorating. Later the GP called me and said mum should be in hospital. Eventually she was taken to hospital and there she tested positive for Covid. She died four days later."

Throughout the pandemic, care homes have faced severe and ongoing challenges in accessing adequate testing to enable them to effectively prevent and contain COVID-19 outbreaks and to identify and manage infections within homes. These challenges resulted from a government failure to prioritise testing in care homes in the early stages of the pandemic, as well as from access and operational failures in the rollout of testing that have resulted in a mismatch between official policy and ministers' rhetoric on the one hand, and the reality on the ground on the other. The need for sustained and continuous testing is necessitated by the high vulnerability of care home residents to outbreaks.

The lack of testing was evident early on in the crisis. On 26 March, Sarah Pickup, deputy chief executive of the Local Government Association, said:

At the moment, there simply isn't access to testing for local authority staff, for care workers or for people resident or in use of social care. We know that the Department of Health and Social Care has got a priority order, starting with critical cases in hospitals and staff nursing those critical cases.¹³⁸

Astonishingly, the government's decision "to urgently discharge all patients who were medically fit to leave hospital," including into care homes, did not include a requirement for these patients to be tested upon leaving hospital or upon entering care homes, despite early evidence of asymptomatic and pre-symptomatic transmission. Up until 15 April, testing for care homes was only available for up to five symptomatic residents.¹³⁹ Moreover, a volunteer at a care home reported that even as late as May her home had an outbreak and that staff struggled to get the tests that were needed.

One volunteer described: "It was the most hideous day where manager found out, she spent seven hours on phone trying to get testing. And PHE and DHSC were just batting [responsibility] back to each other. We got three tests for three residents in the end. All were positive, then we were given full testing: of 23 residents on my wing, 15 were positive."

A care home manager from Hampshire recalled: "We got our first tests on 13 April, but just three. We had about eight or ten residents with symptoms but were told we could not get any more tests. They said 'you just test three residents and if any of them are positive you should treat all the others as if they have COVID and isolate them."

On 15 April routine testing of all patients discharged from hospitals was announced for the first time, requiring that patients be tested up to 48 hours prior to leaving hospital.¹⁴⁰ According to care home managers, this is too far in advance: they fear patients are at high risk of contagion in those 48 hours, which in turn constitutes an enhanced risk for the care home receiving those discharged from hospital.

It was on 28 April that all social care workers became eligible for tests, but the daily number of care home tests was capped at 30,000, including both staff and residents.¹⁴¹ Moreover, even when testing did become available, there were reports of tests going missing, not arriving or not being collected on time, and delays of

¹³⁹ National Audit Office, "Readying the NHS and adult social care in England for COVID-19," 12 June 2020,

www.nao.org.uk/report/readying-the-nhs-and-adult-social-care-in-england-for-covid-19/ ¹⁴⁰ NHS, New requirement to test patients being discharged from hospital to a care home, 16 April 2020,

https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0324-New-requirement-to-test-patients-being-dischargedfrom-hospital-to-a-care-home.pdf.

¹³⁸ House of Commons Health and Social Care Committee, 26 March 2020, <u>https://houseofcommons.shorthandstories.com/HSC-coronavirus-questions-answered/.</u>

¹⁴¹ P. Dunn, L. Allen, R. Humphries, and H. Alderwick, "Briefing: Adult social care and COVID-19: Assessing the policy response in England so far," The Health Foundation, 29 July 2020, <u>www.health.org.uk/publications/reports/adult-social-care-and-covid-19-assessing-the-policyresponse-in-england;</u> National Audit Office, "Readying the NHS and adult social care in England for COVID-19," 12 June 2020, <u>www.nao.org.uk/report/readying-the-nhs-and-adult-social-care-in-england-for-covid-19/</u>.

up to 10 days to obtain results were reported.¹⁴²

It was not until 7 June that every care home for those aged 65 and older had finally been offered testing. A government announcement stated that "we are now able send out over 50,000 test kits a day."¹⁴³ The introduction of critical regular testing for homes was not announced until 3 July.

On 3 July, the Department of Health and Social Care announced: "Staff and residents in care homes for over 65s and those with dementia will receive regular coronavirus tests from next week as part of a new social care testing strategy ... Staff will be tested for coronavirus weekly, while residents will receive a test every 28 days to prevent the spread of coronavirus in social care."¹⁴⁴

However, on 31 July, DHSC acknowledged that it had not been able to meet this goal. It said that "as a result of a numbers of factors including rising demand across testing and unexpected delays we have not been able to reach all care homes for older people and people with dementia as quickly as we had hoped … We will now reach all care homes for older people and people with dementia by 7 September 2020."¹⁴⁵

A care home owner and manager from Durham who spoke to Amnesty International in mid-August said that the provision of testing was still far from adequate. He explained: "It hasn't become clearer – I've tried to get access to testing. We've been all over the shop. We got onto the repeat testing initially ... then it was a different one. There was some testing for care staff and residents but I've no idea what the next few weeks will look like though now."

Another care home manager said, during the same period: "We had the promise of regular weekly testing but it only happened for three weeks and then we got an email on the 4 August saying we cannot test until the 7 of September."

Even by 7 September these problems were far from solved, with care home managers complaining of further delays both in obtaining the tests and in received the results. They reported that in some cases obtaining test results took seven days instead of the promised 72 hours. Similar problems were experienced in the wider community. On 7 September the health secretary apologised "unreservedly to all care homes who have been affected for the upset these issues have caused you, your residents and your staff."¹⁴⁶ On 15 September he again pledged to work to resolve the testing delays but warned that it could take several weeks—during which he pledged to prioritize the NHS and care homes.¹⁴⁷

In addition to failures in obtaining regular testing, care home managers told Amnesty International that they have faced challenges in accessing tests that were available due to arrangements not taking into consideration the capacity issues facing care homes and tests not being available in accessible locations. For example, those using drive-through testing must be in a vehicle on their own. They are not supposed to use public transport or taxis. However, many care workers do not have a car.

INSUFFICIENT PPE AND POOR PPE GUIDANCE

"Member States will need to consider ensuring that the most up to date guidance is provided, and that medical equipment, medications and personal protective equipment (PPE) is procured quickly for both care homes and home care services."

WHO, 21 May 2020.148

- https://www.gov.uk/government/news/covid-19-tests-offered-to-every-care-home-for-elderly-or-those-with-dementia
- ¹⁴⁴ DHSC, "Regular retesting rolled out for care home staff and residents," press release, 3 July 2020,
- www.gov.uk/government/news/regular-retesting-rolled-out-for-care-home-staff-and-residents

¹⁴² House of Commons Health and Social Care Select Committee hearing, 19 May 2020. Q477. www.committees.parliament.uk/oralevidence/407/pdf/.

¹⁴³ "COVID-19 tests offered to every care home for elderly or those with dementia," 7 June 2020,

¹⁴⁵ http://www.careengland.org.uk/sites/careengland/files/DHSC%20Care%20Home%20Testing%20-%20Letter%2031%20July%202020.pdf

¹⁴⁶ Robert Booth, "Government apologises for Covid testing delays at UK care homes," *Guardian*, 7 September 2020, https://www.theguardian.com/world/2020/sep/07/uk-government-apologises-for-care-home-covid-testing-delays.

¹⁴⁷ "Coronavirus: Tackling testing delays 'number one' priority, says minister," BBC News, 16 September 2020, https://www.bbc.co.uk/news/uk-54172210.

¹⁴⁸ WHO Europe, "Strengthening the health system response to COVID-19: Preventing and managing the COVID-19 pandemic across longterm care services in the WHO European Region," 21 May 2020, https://www.euro.who.int/en/health-topics/Health-

"Some of our problems around transmission no doubt related to PPE and, very sadly, some of the deaths too."

James Bullion, deputy chair of the Association of the Directors of Adult Social Services (ADASS), 19 May 2020.¹⁴⁹

"At the moment, even now, we are still in a position where people are not getting enough PPE. First, we need to have the commodities of PPE. Secondly, we need much clearer guidance delivered by Public Health England and others. The third thing we need is a national strategy on this."

Professor Martin Green, chief executive of Care England, 19 May 2020.¹⁵⁰

Challenges regarding PPE supply have been widely reported in England during COVID-19 in both the health and care sector, including within care homes, putting the health and lives of care home residents and staff at risk. Care homes are in normal circumstances responsible for sourcing their own PPE,¹⁵¹ but they generally only use small quantities and therefore do not have large established supply chains. Consequently, and due to national supply challenges, during COVID-19 care homes have needed government support to meet demand.¹⁵² Yet despite repeated and urgent calls by the sector since March,¹⁵³ in a survey of 2,800 carers in April by ITV News, 54% said they did not have enough PPE to do their job safely,¹⁵⁴ while as late as May, 90% of care leaders reported that they required 'greater and more efficient access to PPE' to support the pandemic response.155

The lack of access to adequate PPE has undoubtedly put care home workers at risk. ONS data shows that just over half of all health workers deaths in the UK are social care workers—including care home workers and that they are two to three times more likely to have died from COVID-19 than the general working population.156

Insufficient and unclear guidance regarding PPE is another important problem, care home managers and staff told Amnesty International.

A family member from Wiltshire said: "The carers didn't have proper PPE. [one of carers] told me they didn't have gowns, only the small aprons which they normally use for serving food. That can't be enough protection. Hospital staff who work with COVID patients we saw on TV wear full gowns. Why don't carers have the same?"

Most care home staff and managers interviewed by Amnesty International said they had faced difficulties in obtaining PPE through their usual suppliers. Some reported being told supplies were on reserve for the NHS and could not be provided to them. Care England has also reported incidents of supplies ordered by care homes being requisitioned for the NHS.

A care home manager from Norfolk said: "[In March] we tried to order PPE. We normally have aprons or gloves on hand but did not have the numbers needed. We were getting in touch with our usual suppliers but they were saying 'we can't give them to you they're on order for the NHS' ... We couldn't get hold of [PPE] for love or money."

A care home owner and manager in Durham said: "We would have struggled to get PPE through the Local Resilience Forum ... We were trying to buy from others but they were telling us they were for the NHS".

On 26 March 2020, Professor Martin Green, chief executive of Care England, told the UK Parliament Health

153 Local Government Association and Association of Directors of Adult Social Services. Letter to Matt Hancock on 27 March 2020 regarding 'Urgent: PPE provision for the adult social care sector,' www.local.gov.uk/letter-secretary-state-matt-hancock-lga-and-adass ¹⁵⁴ Paul Brand, "Exclusive poll shows true extent of coronavirus crisis in care homes," ITV News, 17 April 2020,

https://www.itv.com/news/2020-04-17/exclusive-poll-shows-true-extent-of-coronavirus-crisis-in-care-homes

¹⁵⁵ ADASS Coronavirus Survey (2020).

systems/pages/strengthening-the-health-system-response-to-covid-19/technical-guidance-and-check-lists/strengthening-the-healthsystems-response-to-covid-19-technical-guidance-6,-21-may-2020-produced-by-the-who-european-region Ibid.

¹⁵⁰ House of Commons Health and Social Care Select Committee hearing, 19 May 2020.

¹⁵¹ DHSC, COVID-19 Adult Social Care Action Plan, www.gov.uk/government/publications/coronavirus-covid-19-adult-social-care-actionplan/covid-19-our-action-plan-for-adult-social-care ¹⁵² Health Foundation, p. 11.

¹⁵⁶ 'Deaths involving the coronavirus (COVID-19) among health and social care workers in England and Wales, deaths registered between 9 March and 20 July 2020', ONS,

https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/adhocs/12112deathsinvolvingthecoronavirusco vid19amonghealthandsocialcareworkersinenglandandwalesdeathsregisteredbetween9marchand20july2020

and Social Care Select Committee:

We have also heard that the [PPE] some of my care members ordered some time before this crisis are being taken at the borders for the NHS. We have a situation where even the normal areas of supply are not getting through, and the PPE that is coming through at the moment is only a short-term measure ... If we have a national stock, we must make sure that it is cascaded right across the system. Obviously, the NHS has needs, but so does social care.¹⁵⁷

All care home managers interviewed by Amnesty International said PPE costs had increased dramatically up to 16 times as much—and securing supplies had been extremely difficult at the height of the pandemic when the need was greatest. As one care home manager explained, "A box of 50 masks was £5 before COVID and now it is £25-30, and at the height of pandemic it was up to £80. Now there is no VAT on PPE, but when VAT is re-imposed it will add another 20% to prices."

Another care home owner and manager recalled: "I tried to find out how to get more PPE through the Local Resilience Forum route but they were struggling to provide adequate PPE. If it hadn't been for me pulling on friendships and spending £25,000 to bring masks in air freights [we wouldn't have had enough]."

For councils, accessing the right PPE has been a major driver of additional spending during the outbreak and concern is growing about the impact of these costs on social care finances going forward.¹⁵⁸

James Bullion, president of ADASS, stated in May during a House of Commons Health and Social Care Select Committee hearing:

In relation to PPE, I was very concerned when I came in March—I am still concerned actually—that PPE is the single biggest and most expensive factor in the cost of dealing with COVID in adult social care, both for providers and local authorities. We still do not have an effective supply chain, although the situation has improved since March.¹⁵⁹

Concerns have also been raised about the guidance issued by government on PPE. Up until mid-April guidance advised care home staff to only wear PPE in cases where residents were symptomatic, despite evidence of asymptomatic spread as early as February. It wasn't until 17 April that guidelines on "how to work safely in care homes" recommended using PPE when caring for all residents—including those without symptoms—during sustained COVID-19 transmission.¹⁶⁰ Contradictory guidance around PPE and the pace of the change of guidance was also an issue for managers and staff in being clear when and how to use it.¹⁶¹

POOR, LATE AND CONTRADICTORY GUIDANCE

Since the beginning of the pandemic, concerns have been raised about the timeliness, adequacy, clarity and coordination of government guidance on COVID-19 in care homes. Care home managers and owners have told Amnesty International that as the coronavirus was spreading in Italy and other countries, they took it upon themselves to prepare as early as February, in the absence of guidance from the government. The measures they adopted included closing care homes to outside visitors and making arrangements for sufficient supplies of the PPE they believed would be necessary, based upon their knowledge of handling other infections in their care homes in the past.

Once government guidance started to be published, care home staff, managers and owners reported that it came from multiple sources and was often contradictory.

A care home worker in Norfolk recalled:

The guidance was so conflicting ... Every day new guidance was coming out ... Some was online, some was on PHE's website, we'd get emails from the council, the National Care Association sent out daily

¹⁵⁷ House of Commons Health and Social Care Select Committee hearing, 26 March 2020. Q266. https://committees.parliament.uk/oralevidence/268/default/

https://committees.parliament.uk/oralevidence/268/default/ ¹³⁸ P. Dunn, L. Allen, R. Humphries, and H. Alderwick, "Briefing: Adult social care and COVID-19: Assessing the policy response in England so far," The Health Foundation, 29 July 2020, www.health.org.uk/publications/reports/adult-social-care-and-COVID-19-assessing-thepolicy-response-in-england, and Local Government Association (LGA), "Social care providers face more than £6.6bn extra COVID-19 costs," press release, 4 June 2020, www.local.gov.uk/lga-social-care-providers-face-more-ps6bn-extra-covid-19-costs. ¹⁵⁹ House of Commons Health and Social Care Select Committee hearing, 19 May 2020.

¹⁶⁰ https://www.gov.uk/government/publications/covid-19-how-to-work-safely-in-care-homes

¹⁶¹ House of Commons Health and Social Care Select Committee hearing, 19 May 2020.

emails. There was an overload of information and no one was on the same page. If you spoke with [the council], the next day what they'd say it was out of date ... When Boris Johnson said we hadn't followed the guidance, I was like "which guidance would you like us to follow? The one from this morning or the one sent at 11.45pm last night?"

A care home owner and manager from northern England complained that "when you get a guidance note, it'll be 30 pages – and they don't provide track changes ... There's no time to go through everything."

The CQC also found that "PPE was a challenging area throughout the height of the pandemic. Issues included the pace of change of PPE guidance."¹⁶² Professor Martin Green, chief executive of Care England, reported in May that his members were concerned about getting "endless guidance from various different agencies, much of which has been changing by the day, and, frankly, I do not understand why. We need clear guidance from Public Health England."¹⁶³

In a session of the Health and Social Care Select Committee on 26 March, inconsistencies in guidance between settings were also raised by the Chair, Jeremy Hunt, former Secretary of State for Health and Social Care: "At the moment, the guidance doesn't require PPE to be worn in care homes for non-COVID patients. This puzzles a lot of people, because if those same patients—about 400,000 people across the UK—were living at home, they would be in the shielding category, and all the home care workers who came to look after them—to wash them, get them up in the mornings and so on—would be required to wear masks. So why does the guidance not require that in care homes? Why are we taking that risk with residents in care homes?"¹⁶⁴

FAILURE TO RESPOND TO GAPS IN STAFFING

There is evidence that a range of staffing issues contributed to the spread of infection among and within care homes.¹⁶⁵ Concern has been raised about both the speed and adequacy of government action to address these issues.

According to the National Audit Office, workforce shortage in the care sector pre-pandemic was already estimated at 122,000 and staff absence increased significantly during the pandemic, with absence rates in care homes between mid-April and mid-May 10% on average,¹⁶⁶ and considerably higher in certain care homes or areas. The lack of testing exacerbated this problem as it was impossible to know if some of those self-isolating were COVID-19 free and could in fact work. Staff shortages in turn impacted the ability of care homes to adequately manage infections and the quality of care they were able to provide for residents, both those infected with COVID-19 and others. This was exacerbated by a situation where care home staff had to perform a number of additional tasks—from assisting residents to communicate with their relatives who could no longer visit them, to enforcing social distancing among residents unable to understand the requirement because of dementia, to cutting residents' to nails because chiropodists stopped visiting care homes, to interpreting and communicating residents' symptoms to GPs who were no longer visiting care homes, etc.

Some care home managers told Amnesty International that they organized cover for absent staff from existing staff because they feared that bringing in new staff would increase the risk of contagion. Others, faced with serious staff shortages, had no choice but to rely on temporary/agency staff and to try to recruit new staff.

As a care home manager in Norfolf recalled:

www.committees.parliament.uk/oralevidence/407/pdf/

¹⁶⁴ House of Commons, Health Select Committee hearing, 26 March 2020.

¹⁶⁵ Department of Health and Social Care (2020) Official Statistics: Vivaldi 1: COVID-19 care homes study report [webpage]

 ¹⁶² COVID-19 Insight, Issue 4, CQC, September 2020, https://www.cqc.org.uk/sites/default/files/20200916_covidinsight_issue04.pdf
 ¹⁶³ House of Commons Health and Social Care Select Committee hearing, 19 May 2020. Q477.

www.gov.uk/government/publications/vivaldi-1-coronavirus-covid-19-care-homesstudy-report/vivaldi-1-covid-19-care-homes-study-report;
 Dunn, P, Allen, L, Humphries, R, Alderwick, H (2020) 'Briefing: Adult social care and COVID-19: Assessing the policy response in England so far'. The Health Foundation, 29th July 2020. Accessed on 29.08.20 at www.health.org.uk/publications/reports/adult-social-care-homesstudy-report/vivaldi-1-covid-19-care-homesstudy-report/vivaldi-1-covid-19-care-homesstudy-report/vivaldi-19-care-homesstudy-repo

¹⁶⁶ National Audit Office, "Readying the NHS and adult social care in England for COVID-19," 12 June 2020, www.nao.org.uk/report/readying-the-nhs-and-adult-social-care-in-england-for-covid-19/.

About 20% of our staff were shielding and self-isolating and we needed to cover all those shifts. When the hospitality sector closed we got a flood of applicants but when it re-opened those staff left. Between March-June we hired 21 carers, 18 left in that same period ... We also had agency workers.

Despite a number of measures taken in March to help support the NHS workforce, policy to support the social care workforce was not announced until April.¹⁶⁷ Vic Rayner, executive director of National Care Forum, a membership organisation for non-profit organisations in the care and support sector, said on 19 May:

We have been asking for many months for some of those resources to come into social care, and the fact that, as far as I am aware, we have had a very small number—if any—of those nurse returners coming into the social care environment to date is really problematic. Exactly that kind of expert additional resource at this time of need would provide support for staff, and would provide some additional resource and clinical skills that are desperately needed.¹⁶⁸

Concerns have also been raised about the government's delay in addressing the risk of transmission presented by staff working across different homes. Despite emerging reports of asymptomatic transmission in other countries already in February, a lack of testing and PPE, government advice for care homes in March was for them to "to work with local authorities to establish plans for mutual aid, including sharing of the workforce between providers."¹⁶⁹ It was not until 15 May, over a month after pre-symptomatic cases were reported by WHO and still without sufficient testing or PPE, that the government outlined measures that care homes should take to restrict staff (including agency staff) to working in only one care home where possible, and provided funding to support them in doing so.¹⁷⁰ As Vic Rayner has highlighted, without adequate testing, the consequence of sharing workers across sites has meant that "we end up in a position where staff who have done a most extraordinary and incredible job of supporting people in this very difficult climate end up feeling like they are the people who are responsible for the spread."¹⁷¹

¹⁶⁷ P. Dunn, L. Allen, R. Humphries, and H. Alderwick, "Briefing: Adult social care and COVID-19: Assessing the policy response in England so far," The Health Foundation, 29 July 2020.

¹⁶⁸ House of Commons Health and Social Care Select Committee hearing, 19 May 2020. Q477.

www.committees.parliament.uk/oralevidence/407/pdf/ ¹⁶⁹ This guidance has now been updated but is reported in a number of places, including <u>https://www.insidehousing.co.uk/news/news/care-home-providers-restrict-access-to-residents-amid-coronavirus-fears-65639</u>

 ¹⁷⁰ https://www.gov.uk/government/news/care-home-support-package-backed-by-600-million-to-help-reduce-coronavirus-infections
 ¹⁷¹ House of Commons Health and Social Care Select Committee hearing, 19 May 2020. Q477.

www.committees.parliament.uk/oralevidence/407/pdf/

5. THE SUSPENSION OF VISITS AND FAILURE OF OVERSIGHT

A closed culture is a poor culture in a health or care service that increases the risk of harm. This includes abuse and human rights breaches. The development of closed cultures can be deliberate or unintentional – either way it can cause unacceptable harm to a person and their loved ones.

Care Quality Commission, "Our work on closed cultures."172

What has been set in train is an unofficial, but officially facilitated, evasion of legal obligations ... With friends and family excluded from visiting relatives in care homes, the suspension of inspection has hidden care practices from view and made care homes invisible to scrutiny.

Alison Tarrant, law teacher at Cardiff University and post-doctoral researcher at the University of Kent, and Lydia Hayes, professor of law at the University of Kent, in a blog post discussing the suspension of inspections.¹⁷³

The Care Quality Commission suspended its inspection visits to care homes at the outset of the pandemic. Other monitoring bodies such as ombudsmen also suspended their visits, and care homes stopped allowing normal visits from residents' relatives and friends. The end result was a glaring absence of outside scrutiny,

¹⁷² CQC 'Our work on closed cultures'. <u>www.cqc.org.uk/publications/themes-care/our-work-closed-cultures#:~:text=The%20development%20of%20closed%20cultures,are%20removed%20from%20their%20communities</u>
 ¹⁷³ Alison Tarrant and Lydia Hayes, "The suspension of routine inspections renders care homes invisible to scrutiny and costs lives," London School of Economics blog, 20 May 2020, <u>www.blogs.lse.ac.uk/politicsandpolicy/care-home-inspections-covid19/</u>.

an increase in residents' vulnerability to abuse, and a deepening of their isolation.

VISITS SUSPENDED

Beginning on 16 March 2020, the CQC announced that it would be ceasing its routine inspections of care homes, leaving open only the possibility of visits "in a very small number of cases when we have concerns of harm, such as allegations of abuse."174 In its announcement, CQC said its primary objective was supporting providers "to keep people safe" and so there would be a "shift towards other, remote methods to give assurance of safety and quality of care." Notably, this decision meant that at a time when older people in care homes were most vulnerable-because of the virus and because those who usually advocated on their behalf could no longer visit them-the regulator was largely absent.

Other monitoring bodies also stopped visiting care homes or even monitoring cases. The Local Government and Social Care Ombudsman "suspended all casework activity that demands information from, or action by, local authorities and care providers, in light of the current Coronavirus outbreak" from 26 March to 29 June 2020, justifying the decision as being "in the wider public interest, to protect the capacity of local authorities and care providers to deliver vital frontline services during the current outbreak."¹⁷⁵ The ombudsman later recognized, however, that the suspension of his office's work "came at a cost to people who rely on us to hold councils and care providers to account who have had their statutory right temporarily denied."176

Even local-level authorities, which have a range of safeguarding duties, stopped visiting care homes during the pandemic, according to care home managers and families interviewed by Amnesty International. Likewise, advocates stopped visiting care homes during the pandemic; advocates are appointed by local authorities to represent the interest of care home residents who are under a Deprivation of Liberty Safeguard and whose relatives cannot fulfil that function. An advocate told Amnesty International that carrying out their duties remotely was particularly challenging for advocates because some care home residents' files were not in digital form and therefore could not be easily transferred, and because it was virtually impossible to have a video call with the concerned residents in private as care homes staff had to be present to logistically support the call.

The lack of official visits occurred at the same time as a ban other visits—from family and friends, as well chiropodists, hairdressers, nurses, and others-which were normally an important source of information for the CQC. Expert noted that "[CQC] have been unable to rely on the 'eyes and ears' of visitors to raise the alarm and care workers have been frightened to speak out."¹⁷⁷

Family members raised concerns about the lack of monitoring. A relative in northern England told Amnesty International:

Quality of care has lapsed; there is no supervision, there is neglect. Residents can't go out and they have no chair exercise, no activities. There is now a lounge upstairs after we fought. They can now go and watch mass and now they have finally started doing chair exercise by using a video. We can fight because I know the sector well and because mum does not have dementia and she has her own phone and we speak on the phone and she can tell us what is happening and describe the situation to us. But most of the other residents have dementia. Who can fight for them?

Another relative in the south of the country said: "My mum is deteriorating so fast and she does not look well looked after at all. Whenever I try to engage with the management I get nowhere. I have contacted the CQC, the local authorities, everyone but I have received no response. Nobody is going in [to the care home], so there are no witnesses to whatever is going on."

Care home managers and staff have also expressed concern at the absence of various oversight bodies. A care home volunteer recalled, for example:

¹⁷⁶ Carehome Professional, 26 June 2020 https://www.carehomeprofessional.com/ombudsman-announces-resumption-of-online-

¹⁷⁴ Care Quality Commission, Routine inspections suspended in response to coronavirus outbreak, 16 March 2020, https://www.cgc.org.uk/news/stories/routine-inspections-suspended-response-coronavirus-outbreak

https://www.lgo.org.uk/information-centre/news/2020/mar/lgsco-suspends-complaints-enquiries-of-councils-and-care-providers https://www.lgo.org.uk/information-centre/news/2020/jun/ombudsman-to-resume-taking-new-complaints-online

complaints/ ¹⁷⁷ Alison Tarrant and Lydia Hayes, "The suspension of routine inspections renders care homes invisible to scrutiny and costs lives," London School of Economics blog, 20 May 2020, https://blogs.lse.ac.uk/politicsandpolicy/care-home-inspections-covid19/#Author

A lady [resident] broke her hip but she refused to go to hospital. Everyone tried to persuade her to go but she refused. The care home reached out to [the local authority] safeguarding [team]. They didn't come and see her but they said 'she has right to choose as she has capacity'. Nobody came to see her to make that call though ... The managers were very worried. They felt abandoned. Someone could easily make an accusation.

The CQC itself reported in June that "[d]uring the pandemic there has been an increase in calls to CQC's national contact centre from staff raising concerns about care." ¹⁷⁸ During that time the biggest increase in calls came from staff in adult social care. Between 2 March and 31 May, the CQC received 2,612 calls from adult social care staff raising concerns, compared to 1,685 for the same period in 2019—a 55% increase. Of those calls, 26% related to lack of PPE or other infection control products, 32% related to how infection control or social distancing was being practiced, and 4% were about quality of care being affected by COVID-19.

In response to concerns raised through these means and those arising through the Emergency Support Framework (ESF) CQC put in place to monitor the impact of COVID-19 on staff and people using services, the CQC said they followed up with providers directly, "usually by phone as we have only carried out a small number of physical inspections since mid-March". In June, the CQC reported that in total 17 physical adult social care inspections had been conducted in adult social care settings since 17 March, 11 of which had been as a result of concerns raised by staff or members of the public. This compares to 2,036 inspections carried out for the same period in 2018-19.¹⁷⁹ Considering the increased volume of calls at a time when families were not allowed to visit care homes, the CQC response seems inadequate and inconsistent with their oversight duty.¹⁸⁰ The CQC has said that it has been conducting more "responsive visits" since June and carried out 300 inspections in August,¹⁸¹ and would be implementing a "managed return" to inspection in the autumn. It acknowledged, however, that it is unlikely that it would "return to [its] published frequency of inspection."¹⁸²

POOR PRACTICES, INCLUDING THE FAILURE TO WEAR PPE

Several families told Amnesty International that they were concerned their loved ones were put at risk by poor practices in the care homes where they lived, including the failure to wear PPE, implement proper infection control measures, or take sick leave to self-isolate if suffering COVID-19 symptoms. Several relatives of care homes residents in different parts of the country expressed concern about staff moving between infected and non-infected residents without adequate PPE, staff breaching lockdown guidance, staff and managers failing to report and isolate symptomatic or COVID-19 positive staff members, a lack of transparency about testing results, poor communication with residents' families regarding deaths and the spread of COVID-19 in the care home, and residents being locked up in their rooms for weeks and general neglect of residents' needs. These poor practices seem to reflect to a large extent the increased pressures and demands on staff during this period, and may have been exacerbated by under-staffing, the absence of equipment, lack of adequate sick pay, and pressure from superiors.

Crucially, the suspension of inspections by the CQC meant that there was little meaningful protection against such practices.

Several relatives of care home residents have told Amnesty International that when they had video calls with their relatives or when they had exceptional end-of-life or bereavement visits they witnessed staff not wearing PPE at all or not using it appropriately. A relative in northern England recalled: "During a WhatsApp video call the carer was not wearing her mask and I told her she should keep it on and she said she hates it and would rather get COVID, but she was in my mother's room and then going to someone else's room."

Another relative in Liverpool said: "They called me from the care home and said I could have the end of life visit with my father as he was close to death. I went and wore full PPE, but some staff members only wore

- ¹⁷⁸ https://www.cqc.org.uk/news/stories/regulating-during-COVID-19-why-raising-concerns-about-care-more-important-ever
 ¹⁷⁹ Based on a monthly average of a total of 12,227 inspections reported to have taken place in the year 2018/9. CQC 'Annual Report 2018/9' www.cqc.org.uk/sites/default/files/20190812_annualreport201819.pdf
- ¹⁸⁰ During the same period, CQC undertook 12 inspections in hospitals and three in primary medical services.
- ¹⁸¹ COVID-19 Insight, Issue 4, CQC, September 2020, https://www.cqc.org.uk/sites/default/files/20200916_covidinsight_issue04.pdf
 ¹⁸² CQC. 15 July 2020. <u>www.cqc.org.uk/publications/major-reports/responding-feedback-about-care-services</u> and CQC blog. August 19 2020. www.medium.com/@CareQualityComm/debbie-ivanovas-blog-218cb0c5329b

masks and no gloves, and some wore gloves but no masks."

A care home volunteer explained that in her place of work: "The other thing with PPE is that [the staff] hated it, they didn't want to wear it and weren't wearing properly." Initial government advice to care homes that no personal protective equipment (PPE) was required if the worker and the resident were not symptomatic and failure to ensure adequate provisions of PPE to care homes undoubtedly contributed to perception among some staff that PPE was not crucial, especially in the early stages of the pandemic.

As late as end of June, in one of its rare inspections during the pandemic, the CQC examined conditions in a care home in which safety concerns had been already raised even before the pandemic. It found that:

Infection prevention and control procedures were not following expected guidance and requirements. Staff did not always wear the protective personal equipment such as face masks when in direct contact with people. They did not always follow effective handwashing or any handwashing between contact with different people. This meant people were put at increased risk especially during the COVID 19 pandemic. Staffing numbers were not sufficient to meet people's needs or keep them safe ... Staff did not have time to spend with people and could not always meet people's needs or keep them safe.¹⁸³

Two care home managers and a volunteer told Amnesty International that reasons some staff were not wearing PPE included their own discomfort, not understanding how, when or why it should be used, and the serious challenges it presented in terms of communicating with residents, especially those with dementia.¹⁸⁴ In some cases, care home staff were told not to wear masks or other PPE by their employers, and in others certain equipment was in short supply.¹⁸⁵ In August, the CQC carried out inspections in 300 well-performing care homes, and 59 'high-risk' care homes where issues had previously been raised, and found that effective PPE use was only 'somewhat assured' in 20% of the high-risk homes, and 'not assured' in 10% of them.¹⁸⁶

A serious issue, especially in the earlier stages of the pandemic was staff feeling under pressure to continue to work while symptomatic, including because of pressures from management or due to financial pressures. Several families told Amnesty International of concerns about staff at their relatives' care homes continuing to work while symptomatic. One explained: "One of the carers continued to work for several days while she was saying she had symptoms. She later went off sick with COVID."

Another relative recalled: "One of the carers at my mum's care home told me that she was unwell and wanted to self-isolate but the manager had told her she had to come to work and should not tell her colleagues about her symptoms. I told her she absolutely had to go off work as it could be dangerous for residents and she eventually went off sick."

In one case, a care worker told Amnesty International that an agency worker in the care home received a call from the agency while on shift saying she had tested positive for COVID-19 but they instructed her to finish her shift and not to tell the home.

Others reported management were not telling staff if residents or other staff members had tested positive for COVID-19. Care workers' testimonies published by the charity Compassion in Care include the following:

"I came in to work and we had a handover. I was doing my usual duties and one of the seniors who had just gone off shift came towards me and took me aside, 'I don't know what to do but X has tested positive for COVID-19, we have been told not to say anything to the other staff but I cannot do it. Please don't say I told you, but they don't want anyone being told, not the staff or families as it makes the home look bad to have another case'. I felt sick they had done this, to not tell us how could they be so stupid. What about us we are only allowed proper PPE if we are attending to someone who might have the virus. All I could think of was how many times have we been in there,

183 CQC report, 28 July 2020, https://www.cqc.org.uk/location/1-370450654/reports

¹⁸⁴ Amnesty International interviews, August and September 2020

https://www.cqc.org.uk/sites/default/files/20200916_covidinsight_issue04.pdf

¹⁸⁵ 'Worthing care home cleaner banned from wearing coronavirus face mask: 'I think it's dangerous'', Worthing Herald, 16 April 2020, <u>https://www.worthingherald.co.uk/news/people/worthing-care-home-cleaner-banned-wearing-coronavirus-face-mask-i-think-its-dangerous-</u> 2540313

¹⁸⁶The CQC found that in some care homes "there were instances where it was only one member of staff who was not using PPE correctly, through to no consistency with its use among different staff members", while in one care home "staff were not changing masks due to limited supplies", 'COVID-19 Insight, Issue 4, CQC, September 2020, https://www.eco.org/uk/siteo/double/file/apt/siteo/20200016 e.org/dipat/siteo/double/file/apt/siteo/20200016 e.org/dipat/siteo/double/file/apt/siteo

when did I go into X's room and who did I come into contact with after that? I had to tell the other staff."¹⁸⁷

Managers and families told Amnesty International that some staff did not inform management they had symptoms because if they went off sick or in self-isolation they would only receive the minimum statutory sick pay (£95.85 a week). In June UNISON, the public service union, expressed concern that:

Staff in the care sector, who need to self-isolate, shield or have the virus, have told UNISON they're being forced to take unpaid leave or survive on minimal statutory sick pay (SSP), leaving them hundreds of pounds out of pocket each week. Some have been told by their employers to use up annual leave or make up time for free when they return to work ... It means a significant number have no choice but to carry on working against public health advice because they can't afford time off, increasing the risks of spreading the virus at work and to their family.¹⁸⁸

A wide range of care home staff were affected. A survey of registered nurses and managers in care homes undertaken by the Queens Nursing Institute reported that only 62 of 163 interviewees could take time off with full pay, while 15 felt pressure not to take time off at all. Care workers with significantly lower pay – often on or around the minimum wage - and more precarious contracts are likely to have felt even greater pressure.¹⁸⁹

A care home manager told Amnesty International that at the beginning of the pandemic more staff were going off in self-isolation but when they realized that they were only receiving minimum statutory sick pay the trend ended. He did not seem concerned that if staff who should self-isolate did not do so for financial reason, they could constitute a health risk for residents and for other staff. This underscores a point that Amnesty International has emphasized in a range of other contexts, which is that employers should implement generous and flexible sick leave and sick pay policies that are, among other things, supportive of workers' potential needs to self-isolate. It is clear that people are more likely to respect quarantines if they have access to adequate social security benefits.

CHALLENGES OF REMOTE COMMUNICATIONS

With family visits to care homes being suspended, the only way for residents to communicate with their families has been virtually, via telephone and video calls. However, most of the families interviewed by Amnesty International said that remote communications with their loved ones in care homes have been limited and unsatisfactory. They felt their relatives often did not benefit from remote forms of interaction, and they also complained that audio and video calls were infrequent and poorly organised. These problems were especially marked for care home residents with dementia.¹⁹⁰ The two most frequent complaints from families were that functioning wi-fi, or devices for video calls, were still not available in care homes, even weeks after visits were suspended (forcing families to rely on sympathetic carers willing to use their personal phones to connect them to their relatives), and that carers were often too busy to enable such calls. They also noted that when such calls did take place, there were privacy issues due to carers having to be present to hold or manage the device.

One relative in Oxfordshire described her efforts to stay in touch remotely: "Communication with my mum has become much more difficult. When we do video calls my mum just cries; it's heart-breaking."

The daughter of a care home resident in Liverpool told Amnesty International that between 16 March and 2 May, when her father died, she was only able to have two short video calls with him. On the day her father died she was told staff were too busy to take the phone to him and she was not informed when he was given end-of-life drugs, even though she was his main carer. She recalled:

I called and asked to speak to him and they said they were too busy. They used to put photos on Facebook of my dad holding a paper saying: "I miss you". It was heart-breaking. Every time I rang to

 ¹⁸⁷ 'Covid Crisis Special Report 10', Compassion in Care, <u>www.compassionincare.com/sites/default/files/covidreport%2010%20final.pdf</u>
 ¹⁸⁸ 'Care worker pay deductions must be tackled to stop hardship and control virus spread', UNISON, 15 June 2020
 <u>https://www.unison.org.uk/news/press-release/2020/06/care-worker-pay-deductions-must-tackled-stop-hardship-control-virus-spread/</u>
 ¹⁸⁹ 'The Experience of Care Home Staff During Covid-19', The QNI International Community Nursing Observatory, July 2020
 <u>https://cdn.ps.emap.com/wp-content/uploads/sites/3/2020/08/QNI-Care-Home-Report-Advance-Text-Only-Version.pdf</u>
 ¹⁹⁰ "Older people with dementia are used to seeing photos or televisions, but seeing a moving image of a loved one can be extremely confusing and sometimes overwhelming", <u>https://www.caremanagementmatters.co.uk/blog/supporting-people-with-dementia-in-care-homes/</u>

speak to him they had excuses. They kept saying that the iPad was locked away in a cupboard and the activity lady who was off sick had the key. Before lockdown I visited him three times a day every day. He hated the food there, so I used to take him food and non-alcohol beer and newspapers. I used to take him out often. And then when he needed it most, I was not allowed to have contact.

Another relative in the south-west of the country highlighting the lack of preparedness of care homes for the lock down, said: "They only got a tablet six weeks after lockdown. During that time sometimes a sympathetic carer would use her own phone, which they are not supposed to do."¹⁹¹

Some care homes have made real efforts to improve the quality of remote contact between residents and their families. For example, the care lead at a small care home in Lancashire told Amnesty International:

We set up a room for residents to have video calls with their families. The video calls are on a big TV screen so residents don't need to fumble with a small screen unable to see their relative/s on the screen properly. They can sit in a dedicated room in private, with no need for staff to be there to hold up iPad/phone, with a cup of tea in a comfortable chair seeing their relatives on a big screen. We also organize virtual joint activities and competitions with other care homes.¹⁹²

Not all care homes have made the same effort, however. Several families told Amnesty International that at the height of the pandemic their relatives and/or other residents in care homes were confined to their rooms for prolonged periods of time—weeks at a time in some cases. One relative recalled: "I called my mum's care home and spoke to the manager who told me proudly that they were doing well and that 'everybody is locked up in their rooms'. My heart sank at the thought of my mum locked up in her room for days and weeks on end."

THE DEVASTATING IMPACT OF PROLONGED ISOLATION

Every single one of the family members and care home staff interviewed by Amnesty International expressed concern that the prolonged isolation of care home residents from their families and friends—and from the outside world—has had devastating consequences. Many feel that the lack of stimulation and social contact has caused significant deterioration in residents' physical and mental health and wellbeing. Relatives and care home managers have told Amnesty International that many residents have suffered loss of movement, reduced cognitive functions, reduced appetite, and loss of motivation to engage in conversation and other activities which they used to enjoy before lockdown. The closure of care homes to outside visitors and the restriction on movements inside care home, as well as the increased demands upon staff in regard to IPC and the provision of care to residents with COVID-19, has also resulted in increased isolation and neglect of residents in some cases.

A family member described her mother's decline in a care home in Worcestershire:

I have not been able to visit my poor mum for six months. She is bed-bound and is on the first floor so window visits have not been possible—her room is right next to a fire exit so I could go to her room without having to pass through the home but "bedroom visits" are not allowed. I have been informed [by the manager] by email "that I will only be able to visit when she is dying". I Skype her but she no longer knows my name and asks where I am and why I haven't visited. During my calls a young carer sits on her bed and holds her hand. She is wearing a face mask but no gloves. She will then go into another resident's room and then another before returning home to her family. It makes no sense at all. These guidelines are being implemented with no thought of the consequences.

Another family member in Yorkshire said:

For five and a half months I only had window visits and during the last window visit I touched my mum's hand through the small window opening, having first used hand sanitizer. I did so because mum was in pain and was crying. A carer saw this and my mum was put in isolation for two weeks. My mum already had COVID two months earlier and both my mum and I tested negative two days after the incident, but

¹⁹¹ According to the NHS Data security and protection toolkit, only digital devices belonging to care homes can handle resident data; personal devices should not to be used. See <u>https://www.dsptoolkit.nhs.uk/.</u>
¹⁹² <u>https://www.kepplegate.co.uk/news/care-home-enjoys-virtual-meetings-during-lockdown</u> and <u>https://www.kepplegate.co.uk/news/adam-</u>

¹³² <u>https://www.kepplegate.co.uk/news/care-home-enjoys-virtual-meetings-during-lockdown</u> and <u>https://www.kepplegate.co.uk/news/adam-works-to-connect-the-country-s-care-hoems</u>

despite this she was still kept in isolation for the full two weeks. This is unnecessary and cruel. Before lockdown my mum was mobile and I used to take her out often, but since lockdown she has been kept in a wheelchair and has deteriorated sharply. Yesterday I had the first garden visit and for the first time she could no longer have a conversation.

A care home volunteer told Amnesty International:

It's extremely isolating. Some of the residents would only have contact with staff fleetingly, just from them coming in and out of the rooms ... The home really tried to keep in touch with families, but they didn't have a receptionist and were incredibly short staffed. There are two activity coordinators but they were off. It meant we were left with only one person for support communication with families.

The same volunteer reported that these restrictions made a number of residents angry. One said she "didn't want to be there, she was angry and felt scared". Coming out of the pandemic, with a number of the restrictions still in place, she said residents are suffering from "severe depression", there are "people just wanting to give up". She reported that others "want out", "they feel neglected".¹⁹³

The damaging impact of loneliness and isolation on older people, especially those suffering from dementia – the majority of care home residents—has been well documented.¹⁹⁴ The problem has dramatically worsened during the COVID-19 pandemic. "My mum can't understand why we have abandoned her ... [and] the loneliness causes her condition to deteriorate more and more. She doesn't want to go out of her room anymore. We are losing her," one family member explained.

The family member of another care home resident in northern England said:

After not seeing mum for months I found her terribly weakened, both physically and mentally. We were sitting in the garden several meters apart and she was crying all the time. Communicating at a distance is exhausting for her as she can't hear properly. Mum doesn't have dementia and before Covid used to have a lot of visitors, friends who live nearby visited every day. Now she has lost the will to live.

As restrictions were lifted throughout the country care homes also started to allow visits in some form over the summer, mostly in care homes gardens. In the absence of government guidelines, the Care Provider Alliance (the national body representing voluntary, private, and community sector care providers) produced its own visit protocol in June.¹⁹⁵ Government guidelines issued on 22 July, adopted much of the language of the Care Provider Alliance protocol, but introduced more stringent restrictions: "where visits do go ahead, this should be limited to a single constant visitor, per resident, wherever possible."¹⁹⁶ Updated guidelines in the Adult Social Care Winter Plan include provision to: "supervise visitors at all times to ensure that social distancing and infection prevention and control measures are adhered to", which may limit privacy.¹⁹⁷ Relatives and care home managers have told Amnesty International they feel the guidelines are excessively restrictive and damaging to the physical and mental health and wellbeing of residents. Some care providers have developed their own guidelines trying to provide more and better access for relatives, including the "Essential Family Carer (EFC) scheme" to enable residents to have more meaningful visits from one relative.198

¹⁹⁵ See, for example, <u>https://careprovideralliance.org.uk/coronavirus-visitors-protocol</u>.

¹⁹³ Examining a similar set of restrictions on family visits imposed in care homes in Australia during the first months of the pandemic, Human Rights Watch drew attention to their negative impact on residents' physical and mental health, and recommended that the Australian government ensure that, going forward, residents are allowed physical visits from family members. Human Rights Watch, Submission to the Australian Royal Commission: Inquiry into Aged Care Quality and Safety on the Impact of the Coronavirus (Covid-19) on the Aged Care Sector, 5 August 2020. https://www.hrw.org/news/2020/08/05/submission-australian-royal-commission 194 "Loneliness and Isolation in Long-term Care and the COVID-19 Pandemic," May 2020. https://www.jamda.com/article/S1525

⁸⁶¹⁰⁽²⁰⁾³⁰³⁷³⁻X/fulltext, and "Mental health of people living with dementia in care homes during COVID-19 pandemic," International Psychogeriatric Association 2020. See also Samantha K Brooks, Rebecca K Webster, Louise E Smith, Lisa Woodland, Simon Wessely, Neil Greenberg, and Gideon James Rubin, "The psychological impact of quarantine and how to reduce it: rapid review of the evidence," The Lancet, February 2020, https://doi.org/10.1016/S0140-6736(20)30460-8.

¹⁹⁶ https://www.gov.uk/government/publications/visiting-care-homes-during-coronavirus/update-on-policies-for-visiting-arrangements-incare-homes and 'Update on policies for visiting arrangements in care homes', DHSC, 21 September 2020,

https://www.gov.uk/government/publications/visiting-care-homes-during-coronavirus/update-on-policies-for-visiting-arrangements-incare-homes ¹⁹⁷ 'Adult social care: our COVID-19 winter plan 2020 to 2021', 18 September 2020,

https://www.gov.uk/government/publications/adult-social-care-coronavirus-covid-19-winter-plan-2020-to-2021/adult-social-care-ourcovid-19-winter-plan-2020-to-2021 ¹⁹⁸ See, for example, <u>https://www.mha.org.uk/news/latest-news/news_archive/coronavirus-COVID-19/</u> and

https://www.mha.org.uk/files/2615/9707/4083/MHA More than just a visitor. A guide for Essential Family Carers.pdf

A care home worker who manages care of residents with dementia told Amnesty International:

Looking after our residents properly doesn't mean only preventing COVID infections - and denying them any quality of life in the process. They have a right to live with dignity, not just survive. Regular, frequent testing for the residents and those who come into contact with them is crucial for protecting vulnerable residents, along with use of PPE, good hygiene, and contact tracing and a good risk assessment relevant to the local reality. If we do that there is no reason that we can't open up to more visits and activities.

The daughter of care home resident In Dorset raised the following concerns:

First they endangered older people in care homes by discharging infected patients into care homes, without even providing tests and PPE, and now they are only interested in preventing more COVID infections and don't look at the damage isolation is causing to care home residents. Isolation is killing people slowly and making their lives not worth living in the meantime.

All the families interviewed by Amnesty International whose relatives are currently in care homes have said that the current restrictions on visits—one visitor per resident and no possibility of holding hands—are excessive and make little sense. They point out that care home staff can interact normally in the community and are only tested once a week at most, while having sustained physical contact with residents.

Care home managers have told Amnesty International that they also consider the government guidelines too restrictive but they fear that if they do not abide by the guidelines they could face a host of problems—from being sued for failing to take precautions against infections, to losing insurance cover and consequently their licence to operate. In fact, the government guidelines do allow care homes some discretion. For example, with regard to the one visitor only, the guidance states that: "To limit risk, where visits do go ahead, this should be limited to a single constant visitor, per resident, wherever possible."¹⁹⁹

Interpretations of the guidelines vary. Some care homes interpret this rule as applying to indoor visits only, while others apply it to garden visits as well. Some care homes are only allowing garden visits. Many, possibly most, care homes are not allowing room visits, which means that many bed-bound residents have had no visits for six months. At the other end of the spectrum, a care home manager told Amnesty International that at his care home they have offered relatives the possibility to store a set of clothes at the care home, so that they can change on arrival and thus avoid using gowns during indoor visits, allowing them closer contact with their loved ones. But many care homes take the more restrictive approach, and some have restricted visits since the government guidelines were issued. As one family member described, "[w]hen visits resumed after lockdown I could visit mum with my siblings but then that was stopped and only one is allowed."

Enabling more frequent, better quality visits inevitably requires more material and human resources, which in turn can mean higher costs. A care home worker explained:

We do need better, less restrictive government guidelines, to ensure that residents can have better quality visits and also activities outside the care homes. This is achievable, while keeping residents and staff safe. It requires good risk assessment, preparation and organization. It requires more efforts than some managers are willing to make. That is why it is not happening enough.

Achieving the right balance between allowing care homes residents meaningful contact with their families and managing the risk of infection is undoubtedly challenging. To be sure, the balance may need to be periodically adjusted depending on the level of transmission in the community and the situation of individual residents and of the specific care home. A zero-risk solution does not exist, as even in the absence of family visits, residents are in close daily contact with care home staff who live in the community and are currently only tested once a week. Care home residents should not be subject to blanket restrictions on their private and family life, except for restrictions which are appropriate to their specific circumstances based on individualised risk assessments. All least rights limiting options – including frequent regular testing for care home workers and visitors - should be explored in a process of meaningful consultation with residents,

¹⁹⁹ https://www.gov.uk/government/publications/visiting-care-homes-during-coronavirus/update-on-policies-for-visiting-arrangements-incare-homes

families and staff in order to ensure that the restrictions are proportionate.²⁰⁰ In this context current government guidelines appear disproportionately restrictive.

As one family member emphasised: "My siblings and I would be willing to restrict our social interaction to a greater extent than it is required of the carers who have very close physical contact with my mum, and to be tested as often or more often than the carers in order to be allowed to visit our mother. I cannot understand why it can't be allowed."

Experts have raised other concerns:

To restrict visits not just to one person at a time, but to 'the same family member visiting each time' raises many ethical dilemmas. Will residents (where able) be expected to nominate a favoured visitor? How, for example, can a resident with a surviving spouse and children be expected to make a single nomination? Or, in the case of a resident with cognitive impairment, how will a network of visiting support decide upon who can continue to visit a loved one and who cannot? Designating one person puts significant pressure and demands on that individual that might be better shared between a small group of visitors; it also fails to allow the resident any choice or preference about who they might wish to see.²⁰¹

It is understandable that care home providers may be concerned about the reputational and financial implications of having further COVID-19 outbreaks in their care homes, especially if these result in further deaths. However, due regard must be paid to the impact of visiting restrictions on residents' physical and mental health.

²⁰⁰ Also see for example:

^{- &#}x27;Visiting in Care Homes: where now?', by Vic Rayner, Executive Director of the National Care Forum and Caroline Abrahams, Charity Director of Age UK, in the National Care Forum, 22 September 2020 <u>https://www.nationalcareforum.org.uk/blog-posts/visiting-in-carehomes-where-now/</u>

^{- &#}x27;Something to Live For?', by Julia Jones, co-founder of John's Campaign, 21 September 2020,

https://johnscampaign.org.uk/#/post/something-to-live-for

^{- &#}x27;Care home relatives need to be given key worker status says the R&RA, Relatives and Residents Association, 24 September 2020, https://www.relres.org/rra-statement-on-the-winter-plan/

²⁰¹ Melanie Henwood and Bob Henwood, "Care home visits: another area of confusion surrounding the UK's COVID-19 response," London School of Economics (LSE) blog, 10 August 2020, <u>https://blogs.lse.ac.uk/politicsandpolicy/care-home-visits-COVID-19/</u>.

6. WITHHOLDING OF INFORMATION AND LACK OF TRANSPARENCY

To date, the government and responsible public bodies, including NHS England and the CQC, have failed to make public crucial data and information relating to the spread of COVID-19 in care homes. This information will be crucial to assessing the impact of their decisions on the human rights of care home residents, as well as to ensure that failures are identified and addressed, that lessons are learned, and that as the pandemic continues the correct measures are taken to avoid the recurrence of past mistakes.

Essential information and data which the government and key public bodies have failed to provide includes, notably:

- Information on the consideration given to the risks posed to care home residents by the decision of NHS England to urgently discharge all those who were medically fit to leave hospital on 17 March 2020, including those patients who were infected or possibly infected with COVID-19 and were discharged into care homes.
- Full details of reports received regarding restricted access of care homes and/or care home residents to NHS services during the COVID-19 pandemic and what action was taken in regard to them.
- Full details of reports received related to CCGs, GPs or care homes in England attempting to implement blanket approaches to advanced care planning during the COVID-19 pandemic, including in relation to DNACPR orders, and what measures, if any, have been taken to address these.
- All data that would support a comparison of the number and rate of deaths of residents in care homes in England which received patients discharged from hospital, and the number and rate of deaths of residents in care homes which did not receive patients discharged from hospital, for the period of 17 March 2020 to 1 August 2020.

Amnesty International requested this information, as relevant, from the Department of Health and Social Care, from NHS England and NHS Improvement, and from Public Health England. As of the date of publication, it has received no response to its requests, except for a summary response from NHS England and NHS Improvement, which did not provide any of the information requested, with one exception. It restated the information contained in the Government Guidance of 2 April,²⁰² and confirmed that the "Department [of Health and Social Care] did not collect data on the extent to which care homes successfully isolated patients with confirmed or suspected COVID-19 and did not require local authorities to collect data

²⁰² It confirmed that at the time of the mass discharge of patients from hospitals into care home starting on 17 March 2020 "care homes needed to make their full capacity available and that they could admit patients with COVID-19". See 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#section-1-admission.

either".203

Amnesty International has also requested the same information, as relevant, from the CQC, which, as the body charged with oversight of health and social care providers in England, including care homes, would reasonably be expected to investigate actions or situations which may constitute a risk to the safety and wellbeing of care homes residents. The CQC responded, mostly referring to publicly available information. In response to a question on how the decision of 16 March 2020 to suspend routine inspections of care homes was reached, the CQC stated that "Our primary objectives during the period of the COVID-19 pandemic will to be to support [health and social care providers] to keep people safe during a period of unprecedented pressure on the health and care system."²⁰⁴ It also said:

Our main aim is to support providers at an exceptionally difficult time. But we may receive information, either from an external source or through our conversation with a provider, that results in serious concerns about actual or possible avoidable significant harm, abuse, or breaches of human rights. In this case, we will assess the risks involved and decide to either: suggest additional sources of support, arrange a follow-up call, use inspection and enforcement processes as and when necessary.

In late August 2020 the CQC, in response to freedom of information requests by *The Guardian* newspaper, refused to make public which care homes or providers recorded the most coronavirus fatalities, reportedly citing fears that the information could negatively impact the commercial viability of care home providers.²⁰⁵

COVID-19-related deaths are not necessarily a direct indicator of the quality of the care in a given care home. There are a range of other factors associated with COVID-19 transmission in care homes, including notably the level of community transmission, the testing regime, the movement of staff between and within care homes, the implementation of IPC measures, access to and correct use of PPE, and transmission of the virus from those entering the homes from hospitals or other settings. However, the absence of the abovementioned data deprives those who have lost loved ones of information related to their deaths, whilst also depriving older people and their relatives of necessary information to make an informed decision when choosing a care home or care home provider. Crucially, such lack of transparency also impedes accountability for decisions taken by the relevant officials and bodies and hampers efforts to ensure lessons are learned and failures are not repeated, and that people's human rights are respected, protected and upheld.

²⁰³ This was in response to Amnesty International's request for "Information on any assessment made of the capacity and preparedness of care homes to safely receive patients discharged from hospitals from the 17 March onwards who may have had COVID-19, including in regard to their ability to isolate those individuals and provide adequate care".
²⁰⁴CQC letter, 10 September 2020

²⁰⁵ "Data on Covid care home deaths kept secret 'to protect commercial interests'", *Guardian*, 27 August 2020, https://www.theguardian.com/world/2020/aug/27/data-covid-care-home-deaths-kept-secret-protect-commercial-interests

7. DOMESTIC AND INTERNATIONAL LAW

The UK is a state party to international and regional human rights treaties which require it to protect and guarantee fundamental human rights relevant to the concerns addressed in this report, including, notably, the right to life, the right to highest attainable standard of physical and mental health, the right to non-discrimination—including on the grounds of age, disability or health status—the right not to be subjected to inhuman or degrading treatment, and the right to private and family life.²⁰⁶

The UK's obligations under international human rights law requires that it respect, protect and fulfil the human rights of individuals within its jurisdiction.

Most of these rights have been enshrined in UK law by the Human Rights Act, which incorporates into domestic law the rights set out in the European Convention on Human Rights (ECHR).²⁰⁷ These include the right to life (ECHR Article 2); the right to freedom from torture and inhuman or degrading treatment (Article 3), the right to respect for one's private and family life, home and correspondence (Article 8), and the right to protection from discrimination in respect of such rights and freedoms (Article 14). Although the protection of the right to health is not specifically mentioned in the text of the ECHR, obligations of state parties to the ECHR in this regard have been repeatedly affirmed in case law.²⁰⁸ Moreover, the UK is bound to protect the right to health as enshrined in the international human rights (ICESCR),²⁰⁹ and the Convention on the Rights of Persons with Disabilities (CRPD).²¹⁰ The latter instrument protects a range of rights—including the rights to life (Article 10), to health (Article 25) and to equality and non-discrimination (Article 5)—specifically

http://www.ohchr.org/EN/ProfessionalInterest/Pages/CAT.aspx

http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx

²⁰⁶ International Covenant on Economic, Social and Cultural Rights <u>http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx</u> International Covenant on Civil and Political Rights <u>http://www.ohchr.org/EN/ProfessionalInterest/Pages/CCPR.aspx</u> Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment

International Convention on the Rights of Persons with Disabilities

²⁰⁷ 'The Human Rights Act. What human rights are covered by the Act?' <u>https://www.equalityhumanrights.com/en/human-rights/human-rights-</u>

act#:~:text=The%20Human%20Rights%20Act%201998%20sets%20out%20the%20fundamental%20rights,the%20UK%20in%20Octobe

²⁰⁸ "The obligations the Contracting States assume under the Convention are of a negative as well as of a positive kind. Under the negative obligation, a Contracting State must not interfere with the health of an individual unless there is Convention-compliant justification for so doing. A Contracting State may also be required to take measures to safeguard the health of an individual under the so-called positive obligations", in 'Health-related issues in the case-law of the European Court of Human Rights', European Court of Human Rights 2015, https://www.echr.coe.int/Documents/Research_report_health.pdf

²⁰⁹ "The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health". Article 12(1); "The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases; (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness." Article 12(2); ICESCR <u>https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx</u>. See also OHCHR, 'Toolkit on the Right to Health', <u>http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=4slQ6QSmlBEDzFEovLCuW1AVC1NkPsgUedPlF1vfPM12c7ey6PAz2qaojTzDJ</u> mC0y%2B9t%2BsAtGDNzdEqA6SuP2r0w%2F6sVBGTpvTSCbiOr4XVFTqhQY65auTFbQRPWNDxL and 'The Right to Health, Fact Sheet 31', OHCHR and WHO, <u>https://www.ohchr.org/Documents/Publications/Factsheet31.pdf</u>.

²¹⁰ https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-

with regard to people with disabilities.

Realisation of the right to health as protected under the ICESCR requires that health care facilities, goods and services are available in sufficient quantity; accessible to everyone without discrimination, which includes physical accessibility, affordability, and information accessibility; acceptable to all persons, that is, respectful of medical ethics and culturally appropriate; and of good quality. The "participation of the population in all health-related decision-making at the community, national and international levels" is also key.²¹¹

The right to health includes the obligation to take steps necessary for the "prevention, treatment and control of epidemic, endemic, occupational and other diseases". The Committee on Economic, Social and Cultural Rights, has spelled out in detail states' duties flowing from this right, emphasising that "[m]easures to prevent, treat and control epidemic and endemic diseases" are "obligations of comparable priority" to core obligations (or "the minimum, essential levels") of the right to health.²¹²

All affected individuals and communities are entitled to easy, accessible, timely and meaningful information concerning the nature and level of the health threat, the possible measures to be taken to mitigate risks, early warning information of possible future consequences and information on ongoing response efforts. Preventive care, goods, services and information should be available and accessible to all persons, as should treatment and if necessary, supportive care to manage the symptoms and consequences of the virus. Furthermore, in designing responses to COVID-19, states should be conscious of the particular impact of the virus on specific groups of people and ensure that their needs and experiences are fully accounted for in plans and strategies.

Under the ICESCR the state has an obligation to meet the physical and mental health needs of older persons. Notably, it must guarantee access to good quality healthcare services for older persons, including "preventive, curative and rehabilitative health treatment."²¹³

Rosa Kornfeld-Matte, the then-UN Independent Expert on the enjoyment of all human rights by older persons, addressed the situation of older people at the outset of the pandemic, expressing concern that they would face discrimination in accessing medical care. She warned that "decisions around the allocation of scarce medical resources such as ventilators in intensive care units may be made solely on the basis of age, denying older persons their right to health and life on an equal basis with others." She also called for triage protocols to be developed and followed "to ensure such decisions are made on the basis of medical needs, the best scientific evidence available and not on non-medical criteria such as age or disability."²¹⁴

It is worth emphasising that the fact that most care home residents in England are in care homes owned by private, for-profit companies does not in any way lessen the UK government's obligation to ensure the protection of older people in care homes from violations of their rights. This includes the duty to protect against human rights abuse by third parties, including business enterprises. "States must protect against human rights abuse within their territory and/or jurisdiction by third parties, including business enterprises. This requires taking appropriate steps to prevent, investigate, punish and redress such abuse through effective policies, legislation, regulations and adjudication."²¹⁵

Many of the care home residents in England are living with dementia and other conditions which affect mental capacity.²¹⁶ Some are subject to deprivation of liberty safeguards (DoLS) authorisations under the Mental Capacity Act.²¹⁷ The Mental Capacity Act contains specific protection for the rights of people lacking mental capacity. It is essential to ensure that all restrictions imposed on older people in care homes are necessary to prevent harm, and are a proportionate response to how likely and how serious harm will be.²¹⁸ DoLS allow restrictions to be imposed on an individual where the risk of harm is to that individual,

²¹¹ Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 14: The Right to the Highest Attainable Standard of Health, UN Doc. E/C.12/2000/4, 11 August 2000.

²¹² Ibid

²¹³ ICESCR, General Comment 14, para. 25. See also General Comment 6, para. 35.

²¹⁴ https://www.un.org/development/desa/ageing/news/2020/03/covid-19/.

²¹⁵ Implementing the United Nations "Protect, Respect and Remedy" Framework, Guiding Principles on Business and Human Rights, OHCHR; <u>https://www.ohchr.org/Documents/Publications/GuidingPrinciplesBusinessHR_EN.pdf.</u>

 ²¹⁶ <u>https://www.dementiastatistics.org/statistics/care-services/</u>
 ²¹⁷ 'The Mental Capacity Act (2005) (MCA) and deprivation of liberty safeguards (DoLS) during the coronavirus (COVID-19) pandemic',

Updated 15 June 2020; <u>https://www.gov.uk/government/publications/coronavirus-COVID-19-looking-after-people-who-lack-mentalcapacity/the-mental-capacity-act-2005-mca-and-deprivation-of-liberty-safeguards-dols-during-the-coronavirus-COVID-19-pandemic. ²¹⁸ 'Working within the Mental Capacity Act during the coronavirus pandemic', CQC, 26 May 2020 <u>https://www.cqc.org.uk/guidance-</u></u>

providers/all-services/working-within-mental-capacity-act-during-coronavirus-pandemic, and 'Mental Capacity Act (MCA) and the COVID-

rather than to others: this means that blanket bans on movement, visits or outings for example may not be justifiable under DoLS.²¹⁹

Decisions, policies and actions taken by national and local authorities and institutions, as well as by private companies, violated the human rights of older residents of care homes in England. In some cases the UK government was directly responsible for committing the violations, and in other cases the government failed to ensure the necessary oversight to prevent violations by other parties. More specifically, the decision by the UK government (via DHSC) to discharge patients infected or possibly infected with coronavirus into care homes without having ensured that those care homes had the necessary human and other necessary resources (including access to prompt testing for residents and staff and PPE in sufficient quantities and of adequate quality) and the necessary procedures in place to quarantine the newly discharged patients and to protect the care home residents and staff from transmission, violated the UK's obligation to ensure effective protection of the right to life (under Article 2 of the ECHR) and the right to health (under Article 12 of the ICESCR) of care homes residents and staff by taking specific action and by ensuring effective domestic legislative and regulatory frameworks are in place.

The ICESCR recognizes that the realisation of the right to health (among others) will be "progressive" (as opposed to immediate) and according to the "maximum available resources" of the concerned state but—crucially—prohibits "discrimination of any kind" (Article 2).

Under international human rights law, states have the obligation to prevent violations of the right to life by taking measures to address actual or foreseeable threats to the right to life, exercising due diligence to prevent, punish, investigate and redress not only violations by their own agents but abuses by private actors which would negatively impact the right to life. This requires that they pay particular attention to the protection of those most at risk, be they individuals or marginalised or vulnerable communities or groups.

The government's failure to ensure care homes hosting some of the people most at risk of COVID-19 had fair access—at parity with the NHS—to regular testing for residents and staff and PPE in sufficient quantities and of adequate quality during the pandemic violated its obligation to protect the right to life and the right to health of staff and residents without discrimination.

Decisions by some CCGs and GPs to direct care homes to put blanket DNAR on all residents and the government's failure to ensure compliance by CCGs, GPs and care homes with standard DNAR procedures violated the right to life, the right to health and the right to non-discrimination of care home residents, who were subjected to such practices as members of a specific category—older persons with and without disabilities living in assisted facilities.

The decision of GPs not to visit older people in care homes and the government's failure to ensure that care homes residents had full and equal access to medical care and to care in hospitals violated care home residents' right to health and to non-discrimination and possibly their right to life. In cases where not being hospitalized resulted in additional avoidable suffering, it also violated their right not to be subjected to inhuman treatment (Article 3 of the ECHR).

Some restrictions placed on visits to care homes which restrict or impede meaningful contact between care home residents and their families and friends and bar residents from leaving care homes (even just to go for a walk in a park, the countryside, or some other isolated setting), and which are not based on individual risk assessment are disproportionate and may be discriminatory. As such, these restrictions violate care home residents' right to private and family life (Article 8 of the ECHR) and to non-discrimination. Where such restrictions have caused a deterioration of the residents' cognitive abilities and mental health, they also violate the residents' right to health. The government's failure to ensure that care homes residents are protected against arbitrary interference with these rights violates its obligations under the ECHR and other international human rights treaties ratified by the UK.

¹⁹ crisis', SCIE, 25 June 2020, <u>https://www.scie.org.uk/care-providers/coronavirus-COVID-19/mca</u> . $^{\rm 219}$ Ibid.

8. CONCLUSIONS AND RECOMMENDATIONS

The UK government's response to the COVID-19 pandemic violated the human rights of older people in care homes in England. The pandemic is not over and it is therefore all the more important that no effort be spared to establish the factors that resulted in such disproportionate impact on older people in care homes. Lessons must be learned; remedial action must be taken without delay to ensure that mistakes are not repeated; flawed decision-making processes must be reviewed and rectified, and those responsible for negligent decisions must be held to account.

In July 2020 Prime Minister Boris Johnson committed to an independent inquiry into the COVID-19 pandemic "in the future."²²⁰ A full independent public inquiry should be established without further delay— much time has been lost already – and must consider the overall pandemic preparations and response in adult social care and care homes, including a full investigation into actions taken to ensure a comprehensive and timely cross-government response for social care and a review of the adequacy of the funding made available to support adult social care services and care homes in responding to the pandemic. Any public inquiry must be grounded in a human rights framework, recognising the government's international and domestic obligations to uphold the human rights of all.

Crucially, the inquiry should commence with an immediate interim phase which could examine on an urgent basis key policies and decisions that have impacted the human rights of older people living in care homes in England, notably their rights to life, to health, to non-discrimination, to private and family life and to not be subjected to inhuman treatment. This interim phase should be completed as promptly as possible, preferably by the end of November 2020, so that its findings and recommendations can inform the management of care homes as the pandemic continues.

The inquiry's immediate interim phase should include the following steps:

- Expeditiously gather all relevant records, policies, documents, minutes and other relevant material retained by institutions, organisations and officials.
- Summon witnesses to give evidence on oath as to decisions and actions taken, and their appropriateness.
- Ensure the effective participation of care homes residents and their families, including bereaved families.
- Make recommendations on an urgent basis.

The interim phase should aim to establish the following:

• To what extent the decision on 17 March 2020 to urgently discharge hospital inpatients into care home contributed to the spread of the virus and the deaths of care home residents

²²⁰ "Coronavirus: PM promises future independent inquiry," BBC News, 15 July 2020, https://www.bbc.co.uk/news/uk-politics-53419544.

- To what extent access for care homes residents to NHS services during the pandemic, including to general medical services and hospital care, was subjected to restrictions.
- To what extent there was inappropriate use of DNARs by health and care professionals, including the incorrect interpretation of them to mean that a person should not be sent to hospital.
- The reasons for the continued failure to enable and ensure full and regular testing of care home staff and residents up-to and including on 31August 2020.
- The adequacy of the government's support to the care home sector with regard to workforce issues during the pandemic. and the extent to which the limitation of staff movement between homes has been achieved.
- The extent to which the rights and safety of care workers have been upheld during the pandemic, including whether the necessary measures were taken to ensure that they had access to adequate PPE (quantity and quality), guidelines and training (to protect themselves and the residents).
- The extent to which the Care Quality Commission fulfilled its obligations to ensure the safety and quality of care within care homes during the pandemic, and the extent to which its decision to suspend inspections resulted in/contributed to creating an environment which allowed malpractices to occur in care homes.
- The extent to which the Local Government and Social Care Ombudsman fulfilled their obligations to ensure the safety and quality of care within care homes during the pandemic, and the extent to which his decision to suspend casework and receipt of complaints resulted in/contributed to creating an environment which allowed abuses to occur in care homes.
- The adequacy of the measures taken by local authorities to meet their statutory safeguarding duties with regard to care homes during the pandemic.
- The extent to which gaps and delays in the availability of data has hindered efforts to adequately assess and respond to the needs of older people in care homes during the pandemic.

In addition, the DHSC must also ensure that the necessary mechanisms are put in place without delay to ensure:

- That medical decisions are always and solely based on individualized clinical assessments, medical need, ethical criteria and on the best available scientific evidence.²²¹
- Full access for care home residents, staff and visitors to frequent regular testing.²²²
- Adequate and continued supply of PPE for care homes to enable them to comply with national guidance and ensure all staff have undertaken training on its purpose and correct use.
- That employers—whether public or private—provide all care home workers with the necessary grade of PPE and put in place other IPC measures in line with international standards.
- That care home workers continue to form part of the priority groups for COVID-19 testing and have timely and frequent access to testing services for COVID-19 in order to keep themselves and those they care for, safe.
- Adequate mechanism to assess the capacity of care homes to deliver appropriate infection prevention and control, including in regard to their ability to isolate new or returning residents effectively and limiting the movement of staff as much as possible between care homes; and to provide adequate care for residents with COVID-19 and other residents.
- Full and equal access for care home residents to NHS services.
- An urgent and thorough review of all DNACPR forms that have been added to care home residents' file since the beginning of the pandemic to ensure they have been completed with the full knowledge, consideration and consent of the resident and/or their family or legal guardian where they do not have mental capacity according to the terms set out in the Mental Capacity Act. Ensure all staff working in the home understand when and how DNARs/DNACPRs apply and that they do not in themselves indicate that a patient does not want to be taken to hospital or does not want to receive (non-CPR) medical treatment.

 ²²¹ See WHO, <u>https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2020/05/COVID-0Ider-persons.pdf</u>.
 ²²² See WHO <u>https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2020/05/COVID-0Ider-persons.pdf</u>.

- That guidelines for care home visits put the best interests of the residents at the centre, taking into
 account the different sources of risk and exposure and the possible risk-mitigating measures such
 as more frequent testing for care workers, residents and visitors, work protocols and provision of
 adequate grade PPE to minimise risk of infection.
- That care homes are empowered to develop visiting policies which respect and fulfil the residents' human rights and which give voice and agency to them, their families and/or their legal guardians, and which ensure the safety of residents, visitors and staff.²²³
- The adequate representation and involvement of the social care and care home sector in planning and decision-making processes related to matters which impact care homes residents at all levels

While the future of social care more generally is beyond the scope of this investigation, a public inquiry would present an opportunity to examine the multiple underlying and long-term issues facing the sector that have long been neglected and which urgently need to be addressed to ensure the rights of older people and other residents in care homes are upheld in the context of COVID-19 and beyond. Key issues regarding governance, accountability and financing must be addressed and the role of government, voluntary sector, non-profit sector and for-profit businesses in delivering social care to some of the most vulnerable sectors of society must be scrutinised to ensure compliance with its obligations under human rights law to uphold the fundamental rights of care home residents (and all those within its jurisdiction).

²²³ See UN Policy Brief: The Impact of COVID-19 on older persons, May 2020, page 8 :"Ensure that visitor policies in residential care facilities, hospitals and hospices balance the protection of others with their need for family and connection", https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2020/05/COVID-Older-persons.pdf

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THE UK GOVERNMENT'S FAILURE TO PROTECT OLDER PEOPLE IN CARE HOMES DURING THE COVID-19 PANDEMIC

COVID-19 has had a devastating impact on older persons living in care homes in England. 28,186 "excess deaths" were recorded in care homes in England between 2 March and 12 June, with over 18,500 care home residents confirmed to have died with COVID-19 during this period. UK government decisions and failures resulted in violations of the human rights of people living in care homes, notably the right to life, to health and to nondiscrimination. From discharging 25,000 patients, including those infected, into care homes; to denying care homes residents admission to hospital and imposing "do not attempt resuscitation" orders on them without due process, to failing to provide PPE and testing to care homes - older persons living in care homes were abandoned to die. A full, independent public inquiry must be set up without further delay, with an interim phase to commence immediately and report its findings and recommendations by 30 November so that lessons can be learned and measures swiftly taken to ensure older people in care homes are protected. Certain disproportionate restrictions on care homes visit which are causing so much distress to residents must be urgently addressed, including by making testing available to visitors.

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