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COVID-19 mortality and long-term care: a UK comparison

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Itccovid.org

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R code used to create graphs and calculations are available from [this link](#).

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Executive Summary

The impact of the COVID-19 pandemic on the oldest old, especially those within care home settings, has been devastating in many countries. The UK was no exception. This article reviews the path of the COVID-19 pandemic across the UK long-term care (LTC) sector, indicating how it evolved in each of the four home nations. It prefaces this with a description of LTC across the UK, its history and the difficulties encountered in establishing a satisfactory policy for the care of frail older people across the home nations.

The paper makes several contributions. First, it provides an up to date estimate of the size of the adult care home sector across the UK – previous work has been bedevilled by inaccurate estimates of the number of care home places available. It also assembles the limited information that is available on delayed transfers of care and testing of care home residents, both of which played a role in the evolution and consequences of the pandemic. Its most important contributions are estimates of the number and share (the P-Score) of "excess deaths" in care homes in each of the home nations. The P-Scores provide measures that allow comparisons across care home populations of different size. Not only do we discuss the number of individuals affected, we also compare the proportions of care homes in each of the home nations that experienced a COVID-19 infection. The paper also discusses deaths of care home residents outside care homes, largely in hospitals. It reviews the sparse information on deaths at home of people who were receiving social care.

Throughout our narrative, it will become clear that there have been major deficiencies in both the amount and the consistency of data available to clinicians, care sector staff and researchers trying to understand and to alleviate what has happened in care homes. Thus, the final section makes some recommendations about the scope and timeliness of relevant data. Collection of such data would seem to be a necessary condition to inform best practice and thus avoid a repeat of the troubling effects of the pandemic on people who use formal care between March and June 2020.

Main findings:

Size of the UK care home sector

To correct widespread misreporting of the size of the UK care home sector, we collected information from each of the four home nation care regulators. This gave us estimates of the number of care homes and allowed us to estimate the number of care home residents.

- In total, there are 18,075 care homes for adults across the UK. The most recent regulatory reports show 15,481 care homes in England, 481 in Northern Ireland, 1,057 in Scotland and 1,056 in Wales. We estimate that at the beginning of the pandemic period, there were around 500,598 adult care home residents across the UK. Of these, 425,408 were in England, 14,935 in Northern Ireland, 35,989 in Scotland and 23,766 in Wales.¹

¹ See Table 1 for sources.

- There are significant differences in the numbers of care home residents per thousand adults and per thousand older populations across the home nations. These reflect differences in the demography and prevalence of disability at different ages. They also reflect policy differences around the "balance of care" - the extent to which policy is supportive of care home provision relative to domiciliary care or other accommodation solutions.

UK COVID-19 related deaths of care home residents

Across the UK, COVID-19 mortality data are broadly comparable. All four nations use the emergency ICD-10 codes for recording COVID-19 related deaths and publish these data weekly on their respective statistical authority websites. Some, but not all, of these reports provide a breakdown of deaths by location of death (care home, hospital and other), both current and historic. Nevertheless, we were able to assemble comparable data on deaths in care homes for each of the home nations and on the number and share of care homes where an infection took place. We also collected some limited data on deaths of care home residents outside care homes.

- We define the pandemic period from the registration of the first COVID-19 related death during week 11 (ending 13th March) in England up until week 26 (ending 26th June). There are slight differences in the recording of weeks by the nations and it is important to note that each country may have entered the pandemic at different times, and this may affect estimates of excess deaths and P-Scores.
- Throughout this period, 54,510 COVID-19 related deaths were registered in the UK, across all age groups and all locations of death. There were significant differences in COVID-19 related deaths per 100,000 individuals across the UK. These were highest in England, at 84 deaths per 100,000. Northern Ireland's were lowest at 44 per 100,000. In Wales and Scotland, by week 26, deaths per 100,000 individuals stood at 77 and 76 respectively.
- Of all deaths registered as COVID-19 related in the UK, 17,127 (31%) occurred within care homes and at least 21,775 (40%) were accounted for by care home residents. There were differences across the UK. In Scotland, 47% of deaths attributed to COVID-19 occurred in care homes. This compares with 42% in Northern Ireland, 30% in England and 28% in Wales. In terms of deaths accounted for by care home residents, once again there are differences between the home nations. In Northern Ireland, care home residents accounted for 51% of all COVID-19 related deaths, compared to 50% in Scotland, 50%, 39% in England and 34% in Wales.
- Data on the share of care homes reporting at least one case of suspected or confirmed COVID-19 in Scotland show that 65% of all care homes reported cases. This is compared to 44% of all adult care homes in England, 37% in Northern Ireland and 33% in Wales reporting confirmed or suspected COVID-19 cases. It appears that Scotland had the largest share of affected care homes, though some care must be taken with this

conclusion given that it is not clear that all of the home nations use the same definition of an outbreak.

Excess deaths during the pandemic period

Excess deaths are those deaths in excess of some measure of average or normal deaths over some comparable historic period. For deaths in care homes, we used average weekly deaths during the previous 5-year period. The absolute numbers of excess deaths were transformed to P-Scores by expressing excess deaths as the percentage increase over average historic deaths. This allows meaningful comparison between areas that differ substantially by size of population and record COVID-19 related deaths in different ways.

- Using this measure, we find that over our defined pandemic period England had a 38% increase in mortality compared with 29% in Scotland, 22% in Wales, and 20% in Northern Ireland. Breaking this figure down by location of death reveals a 79% increase in mortality over the pandemic period in English care homes compared to 62% in Scotland, 66% in Wales, and 46% in Northern Ireland. Thus, although Scotland had the highest proportion of care homes infected and the highest proportion of deaths attributed to COVID-19 in care homes, it had a lower proportion of excess deaths in care homes than in England or Wales. This may reflect differences in testing practices and death registrations across the nations. Northern Ireland had both the lowest share of care homes infected and the lowest level of excess deaths in care homes.
- Given that, due to the variation in testing procedures and recording of deaths, it will never be possible to unequivocally assign care home deaths during the pandemic to COVID-19 or other causes, the judgement on relative failure or success in handling the pandemic in care homes must ultimately rest with comparative performance in relation to excess deaths. This internationally recognised approach deals both with misdiagnosed deaths and also deaths that have other immediate causes, but which would not have occurred in the absence of the pandemic. By this measure, Scotland, Wales, and particularly England appear to have performed poorly.

Relative impact of the COVID-19 pandemic on the care home population

As the share of adults living in care homes varies between the four nations, comparing the number of deaths of care home residents registered as involving COVID-19 and of excess deaths to the numbers of people living in care homes can show the relative impact of the COVID-19 pandemic among the care home population in the four nations.

- We find that, in terms of deaths registered as involving COVID-19, during our defined pandemic period, deaths of care home residents in the UK represented just over 4% of all care home beds (ranging from 2.6% in Northern Ireland to 5.4% in Scotland). In terms of excess deaths in care homes (and, due to lack of historical data, not including deaths of care home residents in hospital), these represented nearly 5.5% of care home beds in the UK. The share of residents who died would be higher.

Testing strategy in UK care homes

The testing strategy has been characterised by dramatic changes and has followed a similar pattern across all the four nations. Initially, testing was limited to a few residents with symptoms. The focus moved towards testing people discharged from hospitals to care homes and symptomatic staff in mid-April. More recently testing guidelines have been recognising the role played by asymptomatic transmission by both residents and staff. The four nations are all currently committed to regular testing and retesting collected on site. Doubts remain about the implementation of this ambitious strategy, given reports of limited testing capacity and data gaps across the four nations. Alternative approaches based on the rate of infection in the local area and adoption of innovative strategies such as pool testing and saliva-based testing kits should be considered.

Mortality among people using care at home

England is the only UK nation that has released COVID-19 mortality data on those receiving care at home. That data show that throughout the pandemic period there were a large number of excess deaths in the domiciliary setting. The majority of which were not recorded as being COVID-19 related. Overall, the English data demonstrate that, compared to care homes, the overall proportional increase in deaths was greater in the domiciliary setting².

Data limitations

Several data gaps limit our ability to offer a full account of the impact of COVID-19 within the LTC system. Most notable are the gaps surrounding care at home including data on unpaid carers and individuals' choices over purchasing care; accurate and timely data on transfers of patients from hospital and into care homes; reliable data on testing of residents and staff and infection rates in the care home local area; care home level COVID-19 related mortality data.

Going forward, the urgency of the need to invest more resources into the collection of social care data and statistics has never been more apparent. Acting on the key messages and recommendations set out by the Office for Statistical Regulation (OSR) in their reports into adult social care statistics provides a starting point to prepare and ensure the devastating impact of COVID-19 in the care sector is not repeated.

About this report:

We attempt to present comparable data and statistics on the effect of COVID-19 within long-term care (LTC) settings in the UK, with a particular focus on care homes. We begin in Section 1 by providing a background to LTC policy and provision in the UK. In Section 2 we outline the ways each of the UK nations records COVID-19 mortality and the data sources for each. Further, we highlight the additional sources of mortality data on care home residents that are comparable across the four nations. These data sources inform our analysis in the subsequent sections. In Section 3, we describe the path of the pandemic throughout the UK, presenting

² Hodgson et al, 2020. Briefing: Adult social care and COVID-19 Assessing the impact on social care users and staff in England so far. Available [here](#).

data on COVID-19 mortality and the impact of COVID-19 within care homes. In Section 4, we present data on excess mortality - as one of the key metrics to assess the mortality impact of the pandemic and to make robust comparisons between countries - across the UK and by location of death. Section 5 highlights the testing regimes and their evolution. Section 6 comments on the impact of COVID-19 within the care *at home* setting. Finally, Section 7 discusses the findings and concludes.

1. Long-term care in the UK: Background

Deaths among people who use formal long-term care services, particularly residential or nursing home care in the UK substantially increased during the COVID-19 pandemic with the increase occurring in each of the UK's four constituent nations. Additional deaths among people living in care homes have been a common and troubling feature of the pandemic across the world^{3,4}. The main focus of this paper is on COVID-19-related care home deaths, how they evolved in each of the four home nations during the pandemic, and why they were so difficult to deal with. It also raises important and disturbing questions about the availability and comparability of data relating to care homes and their clients across the UK. The paper also discusses deaths among those receiving social care at home: here the information is even more scant and therefore our ability to draw conclusions is weaker.

To set the context for the review, we begin with a short history of the care home sector across the UK. Although there are common roots, devolution has led to some divergence in the structure and regulation of care homes in different parts of the UK.

1.1. What is long-term care?

Long-term care (LTC) encompasses a wide range of services and activities. The World Health Organization defines long-term care as services to ensure that people with or at significant loss of physical and mental capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity⁵. Most LTC in the UK is provided by families and other unpaid carers, and, while some long-term care is provided by the public health care systems, most formal long-term care is considered “social care” provision. In the UK, such care is provided across different accommodation settings. For older people, care

³ See: Comas-Herrera A, Zalakaín J, Litwin C, Hsu AT, Lemmon E, Henderson D and Fernández J-L (2020) Mortality associated with COVID-19 outbreaks in care homes: early international evidence. Article in LTCcovid.org, International Long-Term Care Policy Network, CPEC-LSE, 26 June 2020.

⁴ Salcher-Konrad M, Jhass A, Naci H, Tan M, El-Tawil Y, Comas-Herrera A. COVID-19 related mortality and spread of disease in long-term care: a living systematic review of emerging evidence. *medRxiv*. 2020. doi:10.1101/2020.06.09.20125237.

⁵ <https://www.who.int/ageing/events/world-report-2015-launch/en/#:~:text=30%20September%202015%20%2D%20Comprehensive%20public,population%20ageing%20is%20urgently%20needed.&text=The%20World%20report%20on%20ageing,new%20concept%20of%20functional%20ability>.

homes are the largest of the institutional settings providing LTC, though more individuals receive LTC in their own home⁶.

Care homes in the UK are mostly classed as either residential or nursing homes. Residential care homes provide accommodation and help with personal care tasks such as washing, dressing and toileting. Nursing care homes also provide accommodation and personal care with the addition of 24-hour nursing care on hand. This type of care is provided to people with severe physical, cognitive or learning disabilities, as well as those with complex medical conditions that require care from a qualified nurse. The majority of care home residents (but not all) are older people, a high proportion of whom have dementia⁷. Some care homes provide both nursing and residential care.⁸

Home care encompasses any care provided within a person's own home. This can include home adaptations for example stair lifts and handrails, meals services and telecare services like personal alarms. Home care also includes domiciliary care or home help, which is help from a professional carer who comes into the home to help with tasks such as cleaning, doing the washing up and laundry and gardening etc. Home care also includes personal care at home, that is, help with personal care tasks such as washing, dressing and toileting. Other care services provided in the community include day care, and other services that people who opt for cash payments may contract, for example personal assistants.

1.2. Provision and funding of long-term care in the UK

The institutional structures that support social care across the UK have common historical roots dating back to the role of local parishes in providing relief to the destitute through the various Poor Laws across the UK⁹. Parish councils took responsibility for supporting those for whom unpaid or paid care was not available or suitable. Local authorities replaced parishes as the lowest level of government during the 20th century, inheriting their role in providing social care.

Increased life expectancy in the UK has been accompanied by more chronic disease, long-term conditions and disabilities that particularly affect older people, many of whom have limited access to unpaid care^{10,11}. Thus, LTC for older people has become increasingly important as a share of social care provision across the four nations of the UK.

The major contrast between health care and social care provision in the UK is that the former is provided free at the point of delivery, while the latter is means and needs tested. Thus, throughout the UK, health services are provided free of charge by the NHS. However, aside from school education, local authorities generally charge for the services they provide. Long-term care is no exception. Charges are qualified by a means test: they are waived if individuals'

⁶ Kings Fund, 2018. Approaches to Social Care Funding. Available [here](#).

⁷ <https://ltccovid.org/2020/06/01/updated-report-the-impact-of-the-covid-19-pandemic-on-people-living-with-dementia-in-uk/>

⁸ NHS, Social Care Support Guide, 2020. Available [here](#).

⁹ Abel-Smith, B. (1964). *The hospitals, 1800-1948: a study in social administration in England and Wales*. London: Heinemann.

¹⁰ Kingston A, Comas-Herrera A and Jagger C, for the MODEM project (2018) Forecasting the care needs of the older population in England over the next 20 years: estimates from the Population Ageing and Care Simulation (PACSim) modelling study. *Lancet Public Health* (3): e447–55.

¹¹ Shaw M, Dorling D. Who cares in England and Wales? The Positive Care Law: cross-sectional study, *Br J Gen Practice* 2004; 54: 899-903

assets fall below pre-specified levels. These means tests are particularly relevant for care homes.

Currently in England, those with assets in excess of £23,250 are expected to pay the full cost of their care: those with assets below £14,250 will have all of their costs covered by the local authority, while those with assets between these limits are required to make some contribution to their care home costs. Broadly similar capital limits apply in Scotland and Northern Ireland. The Welsh Government has been increasing the capital limit over time and in Wales it now stands at £50,000 – around double the limit in the rest of the UK. There is no lower capital limit in Wales – users with assets worth less than £50,000 contribute to costs according to their income. Those on the lowest income do not have to contribute at all.

Individuals with housing assets will almost certainly exceed the capital limit in all four nations. Around 65% of all UK adults are owner occupiers and the share is higher among older adults who have more time to increase their housing equity. Therefore, many individuals will be required to pay care home charges which has the effect of rapidly depleting their wealth. For example, weekly care home charges in England are around £655 per week without nursing care, and £937 per week with nursing care.¹² Where these charges are incurred over a prolonged period they are referred to as “catastrophic” care costs and are thought to affect approximately 1 in 10 adults over the age of 65 in England¹³. There is some evidence that owner occupiers are more resistant to care home admission, other things being equal, perhaps because of a desire to retain or pass on their wealth¹⁴.

1.3. Divergence of the devolved governments

Although there are common historical roots and though funding mechanisms are broadly similar, structures for supporting LTC have diverged since the establishment of devolved governments in Scotland, Wales and Northern Ireland in 1998. The establishment of these institutions almost coincided with the 1999 report of the Royal Commission on Long-Term Care¹⁵. It had been established “to examine the short- and long-term options for a sustainable system of funding of LTC for elderly people, both in their own homes and in other settings”. One of its main recommendations was that nursing and personal care - bathing, showering, dressing toileting etc. - should no longer be charged for.

While the recommendation that nursing care should be free of charge was adopted throughout the UK, free personal care was only implemented in Scotland, with all-party support even though it was understood to be expensive. Its supporters argued that if health care costs of people with cancer are provided free by the NHS, then so too should be the care costs associated with dementia. In Scottish care homes, the weekly allowance to cover personal care

¹² See: <https://www.which.co.uk/after-life-care/financing-care/care-home-finance/care-home-fees-akdbv8k3kwln>

¹³ See: <https://webarchive.nationalarchives.gov.uk/20130221121534/http://www.dilnotcommission.dh.gov.uk/our-report/>

¹⁴ McCann M, Grundy E, O'Reilly D. Why is housing tenure associated with a lower risk of admission to a nursing or residential home? Wealth, health and the incentive to keep ‘my home’. JECH 10.1136/jech-2011-200315

¹⁵ See: <https://webarchive.nationalarchives.gov.uk/20131205101144/http://www.archive.official-documents.co.uk/document/cm41/4192/4192.htm>

costs is £180 per week in 2020/21. The real value of these payments declined by 16 per cent between 2002 and 2019¹⁶.

There have been several reviews of the system for funding LTC in England - Wanless¹⁷, Dilnot¹⁸ and Barker¹⁹ - each suggested plausible mechanisms for limiting catastrophic care costs. But the failure to establish a political consensus has prevented progress. A manifesto proposal to increase the capital limit to £100,000 became a poisoned chalice for Prime Minister Theresa May in the 2017 election. It was dubbed a “dementia tax” by Labour and the media and arguably cost the Conservatives their parliamentary majority. She also promised a “green paper” to outline government proposals for the reform of social care funding in England. At the time of writing, mid-2020, that Green Paper has yet to be delivered.

Care home residents may receive cash payments to offset their costs through the Department for Work and Pensions, a UK ministry. Its remit does not carry through to Northern Ireland, but the system there is essentially the same as in the rest of the UK. For example, Attendance Allowance is a benefit paid to those aged 65+ to help with their costs if their disability is severe enough that they need care. It is currently worth £89.15 per week. However, it is not payable to care home residents in Scotland because the free personal care policy was deemed by DWP to violate its eligibility rules.

1.4. Austerity measures and care homes

The austerity policy introduced by the UK government in 2010 following the financial crisis had a severe effect on care home funding. Local authorities in the UK have very limited tax raising powers and are therefore highly reliant on grants from the UK government in the case of England, and from the devolved parliaments in Scotland and Wales. The position in Northern Ireland differs because social care is arranged by five Health and Social Care Trusts which provide integrated health and social care services.

Between 2009-10 and 2014-15, the real value of government grants to local authorities in England was cut by one third²⁰. Adult social care currently accounts for around one sixth of total local authority spending in England²¹. Hence, austerity inevitably caused local authorities to seek ways of reducing their adult social care budget. Given that a substantial share of care home residents do not have sufficient assets to contribute to their care home costs, the local authorities who purchase care on their behalf have considerable care home market power. During the austerity period, they used this power to drive down care home fees for the residents that they supported, making the argument that they were prevented from offering

¹⁶ Bell, D. and Douglas, E. (2020) Submission to Health and Sport Committee Inquiry into Social Care, accessed at: <https://bit.ly/3184dIO>

¹⁷ See: <https://www.kingsfund.org.uk/publications/securing-good-care-older-people>

¹⁸ See: <https://webarchive.nationalarchives.gov.uk/20130221121534/http://www.dilnotcommission.dh.gov.uk/our-report/>

¹⁹ See: <https://www.kingsfund.org.uk/publications/new-settlement-health-and-social-care>

²⁰ Innes, D., & Tetlow, G. (2015). Delivering fiscal squeeze by cutting local government spending. *Fiscal Studies*, 36(3), 303-325.

²¹ See:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/812505/Local_Authority_Revenue_Expenditure_and_Financing_2019-20_Budget_England.pdf

better prices by their financial situation. Owners of care homes were forced to cut costs to survive if they mainly relied on local authority clients for their income. An alternative strategy would be to recruit more 'self-funders' - those who pay for their own care. Unlike local authorities, potential care clients have almost no market power. The Competition and Markets Authority, which assesses whether markets genuinely support consumer interests, estimated that care home fees paid by 'self-funders' are, on average, 41 per cent higher than those paid by local authorities for places in the same care homes²², so effectively self-funders, as well as paying for their own care, are subsidizing local-authority funded residents.

Austerity also affected public spending in Scotland, Wales and Northern Ireland, since they are also heavily dependent on funding from the UK Government, through a complex mechanism known as the Barnett Formula. The devolved parliaments can choose how to spend this funding. However, the low-risk political strategy is to broadly follow the same spending patterns as those in England. In consequence, the Scottish and Welsh governments largely followed the English lead by protecting spending on the NHS, while reducing the funds allocated to local government. The consequence was downward pressure on social care spending, not just in England, but throughout the UK. Having said this, Wales may be the exception where despite downward pressure on spending there have been small real term increases in social care spending over the last decade²³.

1.5. UK Care Regulators

Each devolved nation has an independent regulatory body that has responsibility for the inspection of social care services. In England, that is the *Care Quality Commission*; in Northern Ireland, the *Regulation and Quality Improvement Authority*; in Wales the *Care Inspectorate Wales* and in Scotland, the *Care Inspectorate Scotland*.

The Competition and Markets Authority examined the care home market in 2017 suggesting that consumer interests are not well served by the sector. The system is confusing: arrangements around choice of home, complaints and contracts are somewhat opaque, often leading to confusion for clients, potential clients and their relatives. Further, little is known about levels of satisfaction with care home provision, from either the perspective of the care clients themselves or their family and friends. Each body collects and openly publishes detailed information on care homes. This can include information on the location of the home, the types of services offered, the number of beds available, staffing, care quality and much more. However, the overlap between these datasets is quite small, meaning that cross-national comparisons are difficult.

It became clear throughout the pandemic that there was no publicly available up-to-date estimate of the number of people living in care homes throughout the UK and within the respective UK jurisdictions. This information would of course be crucial in understanding the impact of the pandemic within the sector.

²² See: <https://www.kingsfund.org.uk/audio-video/key-facts-figures-adult-social-care>

²³ See: <https://gov.wales/sites/default/files/statistics-and-research/2019-10/local-authority-revenue-and-capital-outturn-expenditure-april-2018-march-2019-573.pdf>

Table 1 below provides up-to-date, aggregate figures of the number of care homes, number of available places and estimates of the number of care home residents across the UK, for all adult care homes and those for older people (i.e. aged 65 and over). For each UK nation, we obtained these data from their respective independent regulators of social care. We utilise these data to inform several of our subsequent calculations.

	England²⁴	Northern Ireland²⁵	Scotland²⁶	Wales²⁷	UK
Number of adult care homes	15,481	481	1,057	1,056	18,075
Number of care homes for older people	10,894	392	805	643 (2018)	12,734
Number of beds available (all adult care homes)	457,428	16,059	38,614	25,555	537,656
Number of beds available (care homes for older people)	411,272	14,464	35,320	22,466 (2018)	483,522
Number of care home residents (all adult care homes)²⁸	425,408	14,935	35,989 ²⁹ (2017)	23,766	500,098
Number of care home residents (care homes for older people)³⁰	382,482	13,452	32,691 ³¹ (2017)	20,893	449,518
Number of residents per 1000 population aged 65+	41.1	47.5	34.5	35.9	40.4
Number of residents per 1000 population aged 16+	9.4	10.0	7.9	9.2	9.2
Median number of beds available (all adult care homes)	24	32	33	21	-

²⁴ Care Quality Commission, July 2020 available [here](#). Where primary CQC inspection category is residential social care and CQC provider inspection directorate is adult social care. In the case of homes for older people, the CQC service user band of older people applies.

²⁵ The Regulation and Quality Improvement Authority, July 2020, available [here](#) (Residential care homes). Data filtered to include all nursing homes and residential homes for adults. For older people, categories of care I (older age) and/or DE (dementia) apply. See categories of care definitions [here](#).

²⁶ Care Inspectorate Scotland, July 2020, available [here](#). Data filtered to include active Care Home Services, to Subtype not equal to Children & Young People and Service Status. In the case of older people, Subtype equal to older people applies.

²⁷ The authors obtained from Care Inspectorate Wales up to date information on the number of care homes for adults and the number of beds available within those homes as of 30th July. The latest published data from the Care Inspectorate Wales refer to 2018 and is available [here](#). Due to a change in the registration process, information on adult care homes in Wales no longer distinguish between care homes for older adults and care homes for younger adults.

²⁸ Assuming Scotland's 93% occupancy rate for England, Northern Ireland and Wales.

²⁹ Scottish Care Home Census available [here](#).

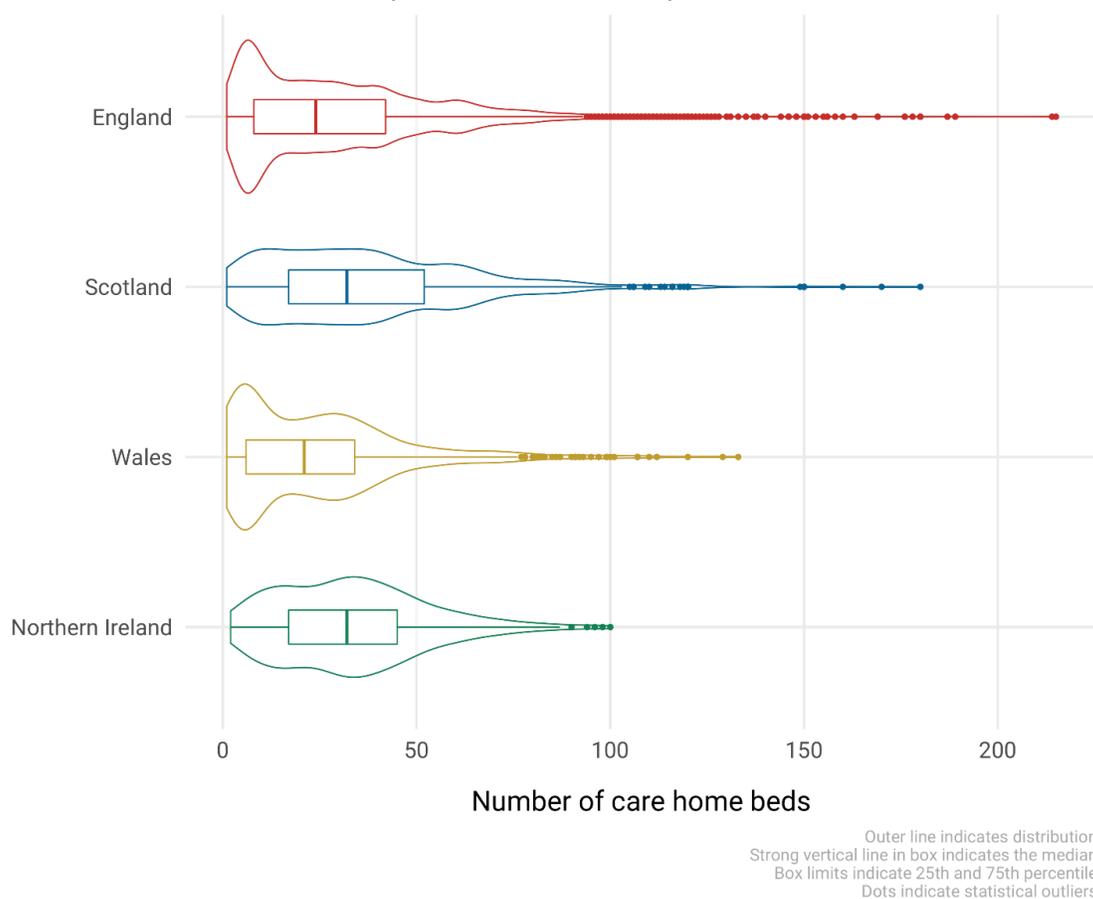
³⁰ Assuming Scotland's 93% occupancy for England, Northern Ireland and Wales.

³¹ Scottish Care Home Census available [here](#).

Table 1 also shows the number of residents per thousand population aged 65+ (because most adult care homes are care homes for older people). It also shows the number of residents thousand population aged 16+ (covering the entire adult care population). These statistics show interesting variations across the UK which reflects the demography and prevalence of disability in each of the home nations and their policy decisions relating to the balance of care between care homes and domiciliary care or other forms of accommodation. Northern Ireland tends to have more care home residents both in terms of its older population and its adult population. Scotland is that the other end of the spectrum with fewer care home residents as a share of its adult and older population than other parts of the UK. This may partly reflect decisions to shift the balance of care towards domiciliary care, particularly after the introduction of free personal care. Wales also has a low number of residents relative to its older population but has a higher share of adult residents (9.2 per thousand population) compared with Scotland (7.9 per thousand population). This reflects relatively high levels of disability among the working age population in Wales. In consequence, its expenditure on this group is relatively high compared with other parts of Great Britain.

Figure 1 below shows the size distribution (based on number of beds available) of care homes for adults for each of the four UK nations. The median number of beds in care homes in Scotland and Northern Ireland is higher than in England or Wales. However, the interquartile range (between the 25th and 75th percentile) in each country overlaps, suggesting the differences in distribution of number of care home beds is not statistically significant.

Figure 1: Distribution of care home size (care homes for all adults)



Source: Care Quality Commission England, Care Inspectorate Scotland, Regulation and Quality Improvement Authority Northern Ireland and the Care Inspectorate Wales.

2. Data and recording mortality across the UK nations

2.1. Recording mortality

As a result of the COVID-19 pandemic, the World Health Organisation (WHO) introduced emergency International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) codes to be used for classifying COVID-19³². Those are 'U07.1- COVID-19, virus identified' and 'U07.2-COVID-19, virus not identified'. The former is assigned to a disease diagnosis of COVID-19 confirmed by laboratory testing. The latter is assigned to a clinical or epidemiological diagnosis of COVID-19 where laboratory confirmation is inconclusive or not available. Both codes can be used for mortality coding as a cause of death.

In the UK, all four nations use the emergency ICD-10 codes for recording COVID-19 related deaths. All nations record the total number of deaths based on a confirmed positive COVID-19 laboratory test and usually publish these on their respective government websites. Moreover,

³² Definition [here](#).

the Office for National Statistics (ONS), National Records of Scotland (NRS) and the Northern Ireland Statistics and Research Agency (NISRA) publish data on both confirmed and suspected COVID-19 deaths, for England and Wales, Scotland and Northern Ireland respectively. These data include further breakdowns for location of death, age and gender. See Table A in the Appendix for details.

2.2. Mortality data sources

In what follows, we provide sources for the main mortality statistics in each of the UK nations and briefly summarise what they contain. An overview of the data is presented in Table A in the appendix.

England and Wales

The Office for National Statistics (ONS) publishes data on deaths registered weekly in England and in Wales [here](#). These data are published 11 days after the weekends to allow time for processing and registration of deaths. The data contain five-year averages of all deaths separately for England and for Wales.

An up to date breakdown of COVID-19 deaths by gender and age using registration date is only available for England and Wales together. However, the ONS also published a breakdown of COVID-19 deaths by age, gender and cause of death for care home residents and the rest of the population for England and for Wales separately, but this data series (available [here](#)) currently only covers up until week 24³³.

The breakdown of deaths by place of occurrence is available for England and for Wales separately and weekly for Weeks 11 onwards. Total deaths since the start of the year by place of occurrence is given separately for England and for Wales.

Weekly data disaggregated by place of occurrence and cause of death (COVID-19 or all causes) for all English and Welsh local authorities (and Welsh Health Boards) are available [here](#) for 2020 (from week 1 to the latest available information).

Moreover, weekly data on five-year average deaths by place of occurrence for English and Welsh local authorities are available [here](#)

Northern Ireland

The Northern Ireland Statistics and Research Agency (NISRA) publish weekly data on deaths registered in Northern Ireland [here](#). These data include five-year averages of all deaths, a breakdown of COVID-19 deaths by gender and age. COVID-19 deaths by place of occurrence are given from Week 11 onwards.

³³ The ONS published data for deaths of care home residents, both COVID-19 and non COVID-19, by place of occurrence (care home, hospital, elsewhere) for England and Wales separately, for the period 2nd March to 12th June (weeks 11 to 24). This data uses the date of occurrence of death rather than the registration of death. The data also present the age breakdown for England and Wales separately, with an aggregated category for children and younger adults (up to the age of 64), while for older people the information is broken down in 5-year categories. This data has been released on 3rd July 2020 and not been updated since.

For the purposes of this report, NISRA also provided a bespoke extract of deaths historical deaths by location for weeks 11-26.

Scotland

The National Records of Scotland (NRS) publish weekly data on deaths registered in Scotland [here](#). Similarly, these data include five-year averages of all deaths, a breakdown of COVID-19 deaths by gender, age and separately by place of occurrence. Unlike the other jurisdictions in the UK, data on deaths by place of occurrence are available from Week 1 in Scotland. Moreover, the five-year average mortality data by place of occurrence are also available from Week 1.

Further, a set of additional spreadsheets is also provided by NRS [here](#). Among them is one that allows COVID-19 deaths to be broken down by gender, age and place of occurrence. As far as we are aware, Scotland is also the only UK nation that is providing this breakdown.

2.3. Mortality data on care home residents

It is important to distinguish between deaths that occur within care homes and deaths of care home residents overall. Whilst many care home residents may die within the care home, some will die elsewhere, e.g. in hospital, and it is important to make this distinction if we are to understand the true impact of COVID-19 on care home residents. Below we outline the sources and describe the data the respective UK nations hold on care home resident deaths.

England

The ONS publishes weekly data on deaths of care home residents, both COVID-19 and non COVID-19, by place of occurrence (care home, hospital, elsewhere, not stated) for England. This is available from 11th April (Week 16) [here](#). These data use notifications of death to the CQC. Also, ONS data on location on death for care home residents occurring between 2nd March and 12th June (weeks 11 to 24) and registered up to 20th June is available [here](#) for England.

Wales

Care Inspectorate Wales produces weekly updates³⁴ covering also location of death for adult care home residents in Wales with confirmed or suspected COVID-19. The data cover the period from 1st March 2020 to the latest available week and it is published by the Welsh Government [here](#). Also, ONS data on location on death for care home residents occurring between 2nd March and 12th June (weeks 11 to 24) and registered up to 20th June is available [here](#) for Wales.

Northern Ireland

The NISRA weekly data on deaths registered in Northern Ireland also include a table of COVID-19 deaths of care home residents by place of occurrence (hospital, care home), from Week 11 [here \(Table 9\)](#).

Scotland

In the set of additional spreadsheets, the NRS publish data on [deaths of care home residents involving COVID-19](#). These data include total COVID-19 deaths up to Week 20, broken down by

³⁴ The updates have been provided every other week since the beginning of August.

location of death (care home, hospital, home, other institution) with the total number of COVID-19 deaths of people whose usual place of residence was a care home but they died in hospital. Note that, unlike the rest of the UK, these data are published as a cumulative total only and not broken down by weeks.

However, since the 27th of May, the Care Inspectorate Scotland is required by the Scottish Government to compile weekly reports on deaths of care home residents, including those occurring in hospital. These weekly counts do not cover the whole period and start from week 22. The figures are disaggregated between confirmed and suspected COVID-19 deaths and other causes. In principle these figures could be compared to NRS data to derive weekly deaths of care home residents by place of occurrence. The weekly data may still differ because of time lags in reporting between the two sources. These reports are updated weekly and can be found [here](#).

2.4. Data on the share of care homes reporting COVID-19 cases

England

In England, Public Health England have published weekly updates on the share of care homes reporting confirmed or suspected outbreaks of COVID-19 since the 9th March. These data and corresponding report are available [here](#).

Wales

In Wales, there are no published figures on care homes reporting confirmed or suspected cases of COVID-19. However, Care Inspectorate Wales was able to supply this data upon request (the information covers cases recorded up until 24th July).

Northern Ireland

In Northern Ireland, the Department for Health provide weekly updates on the number of outbreaks of suspected or confirmed COVID-19 cases in care homes, alongside the total number of care homes with closed cases. An outbreak is defined as there being two or more confirmed or suspected cases in a facility. This data is available in the online dashboard [here](#). Historical data are also available [here](#).

Scotland

In Scotland, since 11th April, the Scottish Government have published weekly data on the number of adult care homes that have reported at least one case of suspected or probable COVID-19 to the care inspectorate. These data are available in Table 7a of the Trends in Daily COVID-19 data available [here](#). Note that these data include all adult care homes and do not provide a distinction between care homes for older people and other adult care homes.

3. The Path of the Pandemic in the UK

The first two confirmed cases of COVID-19 in the UK emerged on the 31st January 2020³⁵. Following this, confirmed cases across the UK continued to rise and on 5th March, the UK reported its first COVID-19 fatality³⁶. As deaths continued to rise, the UK government and the devolved nations began to introduce restrictions and measures to contain the spread of the virus and prepare hospitals for a surge in COVID-19 cases. On 23rd March, the whole of the UK was put in lockdown and the UK Government's message was "Stay at home. Protect the NHS. Save lives". The immediate policy focus was on ensuring that the NHS had sufficient capacity to deal with an expected surge in critically ill COVID-19 cases. One aim was to ensure only those in need of urgent medical care occupied hospital beds therefore moving patients for whom this was not the case to other settings became a high priority.

3.1. COVID-19 mortality across the UK

Deaths from COVID-19 occurred in hospitals and at home as well as in care homes throughout the pandemic period. We define this period from the first COVID-19 death in the UK, which was registered in England during week 11 (ending 13th March), through to week 26 (week ending 26th June). Note that in Wales, the first COVID-19 death was registered the following week and that dates differ slightly for Scotland and Northern Ireland. Specifically, for Scotland, week 11 ends on 15th March and week 26 ends on the 28th June. In Scotland, the first COVID-19 related death was registered in week 12 (week ending 22nd March). In Northern Ireland, week 11 ends on the 20th March and week 26 ends on the 3rd July. Similarly to England, Northern Ireland registered its first COVID-19 related death during week 11.

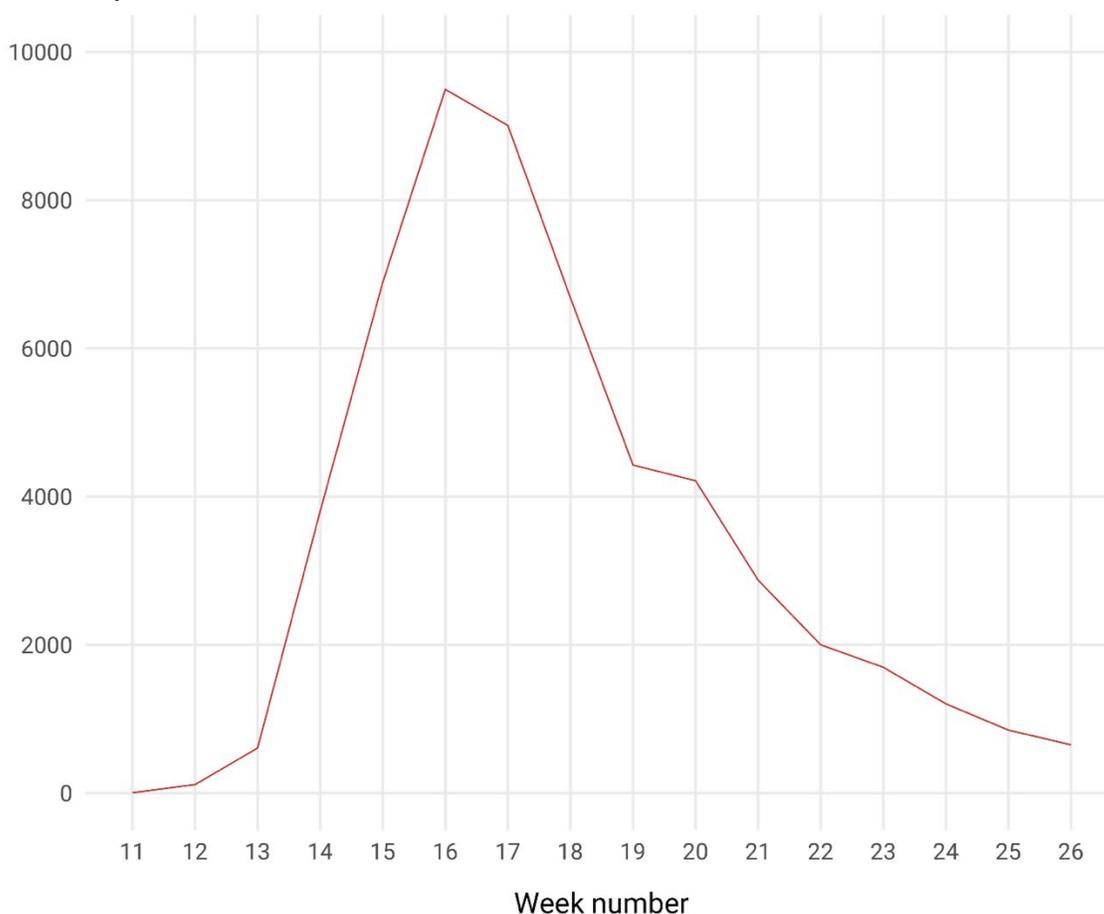
Overall, we do not expect the differences in these dates to change the conclusions in this report, but one should bear in mind that each of the UK nations entered the pandemic at slightly different starting points and follow different conventions in how they number the weeks of the year. Using different start points for each nation would change some values we report, but we believe overall trends and figures would not be significantly altered if this were the case.

Since the first death attributed to COVID-19 during week 11, the number of deaths registered as COVID-19 related increased rapidly, peaking during week 16 at 9,495 deaths, and then declined thereafter. Figure 2 below plots the weekly deaths data between weeks 11 and 26. Total COVID-19 related registered deaths throughout this period were 54,510.

³⁵ <https://www.bbc.co.uk/news/health-51325192>

³⁶ <https://www.bbc.co.uk/news/uk-51759602>

Figure 2: Weekly deaths attributed to COVID-19 in the UK

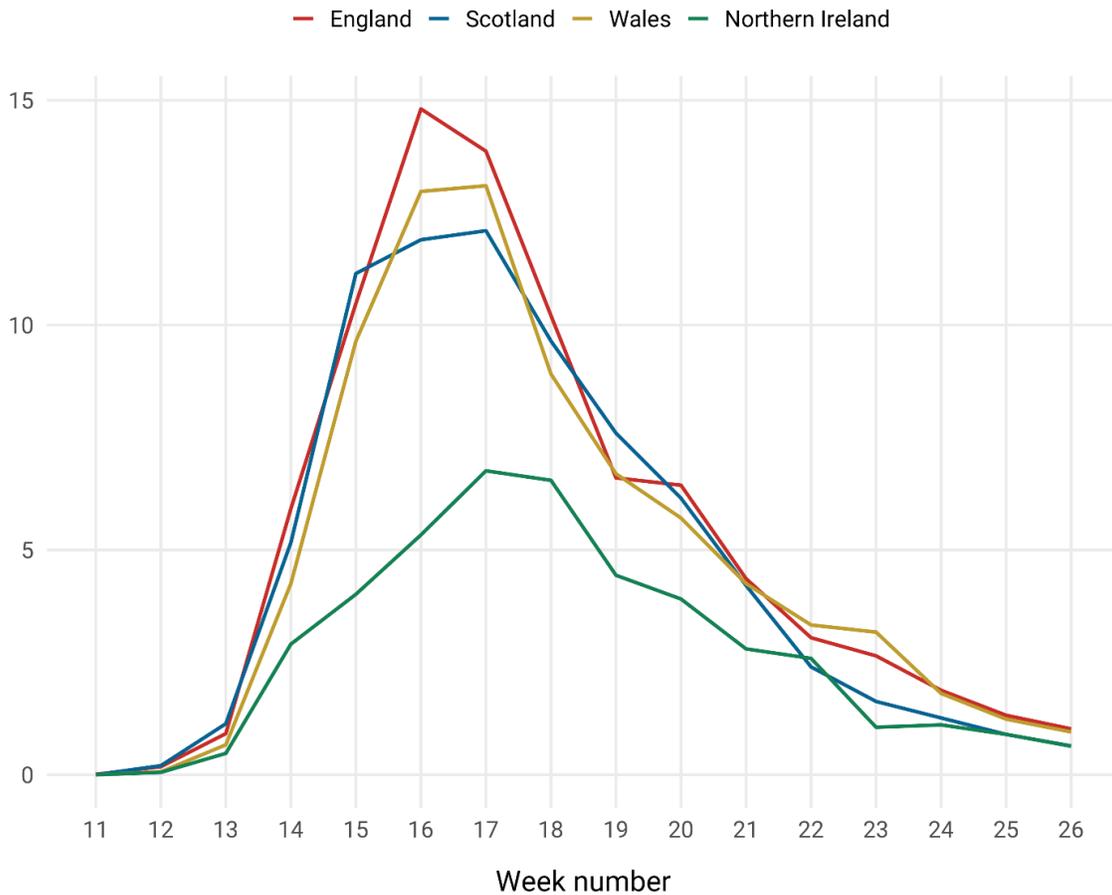


Source: ONS Deaths registered in England and Wales, UK deaths. Available [here](#).

In order to compare COVID-19 mortality rates between the UK nations, it is useful to look at deaths per 100,000 population. Figure 3 plots weekly deaths, again through weeks 11 to 26, per 100,000 population, for each of the four nations. For all nations, the beginning of the rapid increase in deaths began during week 13, with England, Wales and Scotland experiencing a steep incline in mortality for at least two weeks. In contrast, deaths in Northern Ireland increased at a much slower rate and weekly deaths per 100,000 remained noticeably lower right up until the final weeks of the pandemic period.

In England, weekly deaths peaked during week 16 at 14.8 deaths per 100,000 and this was the highest recorded weekly death rate in the UK throughout the entire pandemic period. In contrast, weekly deaths peaked in the rest of the UK during week 17: 13.1 deaths per 100,000 in Wales, 12.1 deaths per 100,000 in Scotland and just 6.8 deaths per 100,000 in Northern Ireland. Note that these figures do not take into account the age structure of the respective nations, though these structures are similar across the whole UK.

Figure 3: Weekly deaths attributed to COVID-19 per-100,000 by UK nation



Source: ONS Deaths registered in England and Wales, UK deaths. Available [here](#).

Table 2 displays total deaths per 100,000 over the pandemic period (weeks 11-26) for the whole of the UK and for the respective jurisdictions. Northern Ireland has notably lower deaths compared its UK counterparts.

	England	Northern Ireland	Scotland	Wales	UK
Deaths per 100,000	84	44	76	77	82

Source: ONS Deaths registered in England and Wales, UK deaths. Available [here](#). ONS Mid-year population estimates. Available [here](#).

3.2. Delayed Transfers of Care

One issue that has been highlighted as a possible contributory factor to the spread of COVID-19 to care homes was the transfer of individuals from hospitals to care homes in the period

leading up to the pandemic. This was intended to “protect the NHS” by freeing beds that were occupied by individuals who were deemed fit for discharge, but for whom no suitable accommodation was available. The process whereby a bed is occupied by someone deemed fit to be transferred from an acute hospital to some other setting because of difficulties in accessing necessary ongoing care, support or accommodation is known as a “delayed transfer of care”. Extended stays in hospital are generally harmful to patient and staff wellbeing as well as having negative impacts on service efficiency³⁷.

Across the UK it is accepted that such delays are not in the interest of the healthcare system because they reduce patient throughput. In 2016/17 there were 2.3 million delayed transfer days in England, costing NHS providers around £173m³⁸. Further, most of these delays are associated with older people, both because they tend to have more complex needs and because they are less likely to have ready access to familial care and support.

In Scotland, the terminology used is “delayed discharges”. These are delays in transfers out of acute hospital settings. This is a narrower definition than that used in England. Delay reasons such as awaiting further non-acute NHS care - the second largest reason for delayed transfers in England – are not counted in Scotland because they do not involve a patient being discharged from hospital.

The home nations have also followed different paths in recording transfers of care during the pandemic. In England and Wales, delayed transfers of care were not recorded. Transfers of care data was halted in February 2020³⁹. The explanation given by NHS statistics was that “*Due to the coronavirus illness (COVID-19) and the need to release capacity across the NHS to support the response, we paused the collection and publication of some of our official statistics.*”

In Scotland, consistent data, based on a monthly census, have been available since July 2016 and continued to be collected during the pandemic. The most recent data from Public Health Scotland cover the period up to and including May 2020. These show a remarkable reduction in delayed discharges between February and March 2020, falling from 1,627 to 1,171 during this period, an overall reduction of 28% (Figure 4). The principal reason for reductions in delayed discharge, accounting for 98% of the total, was “health and social care reasons”, suggesting that Scottish Health and Social Partnerships increased the volume of assessments, placements and care arrangements so that a substantial number of older people whose discharge had been delayed, could be moved into the community or care homes. This was likely associated with a desire to remove patients who were potentially vulnerable to COVID-19 away from hospital settings. Many of the people who were transferred were not tested, which was worrying given the increasing emergence of evidence on the asymptomatic nature of the virus⁴⁰.

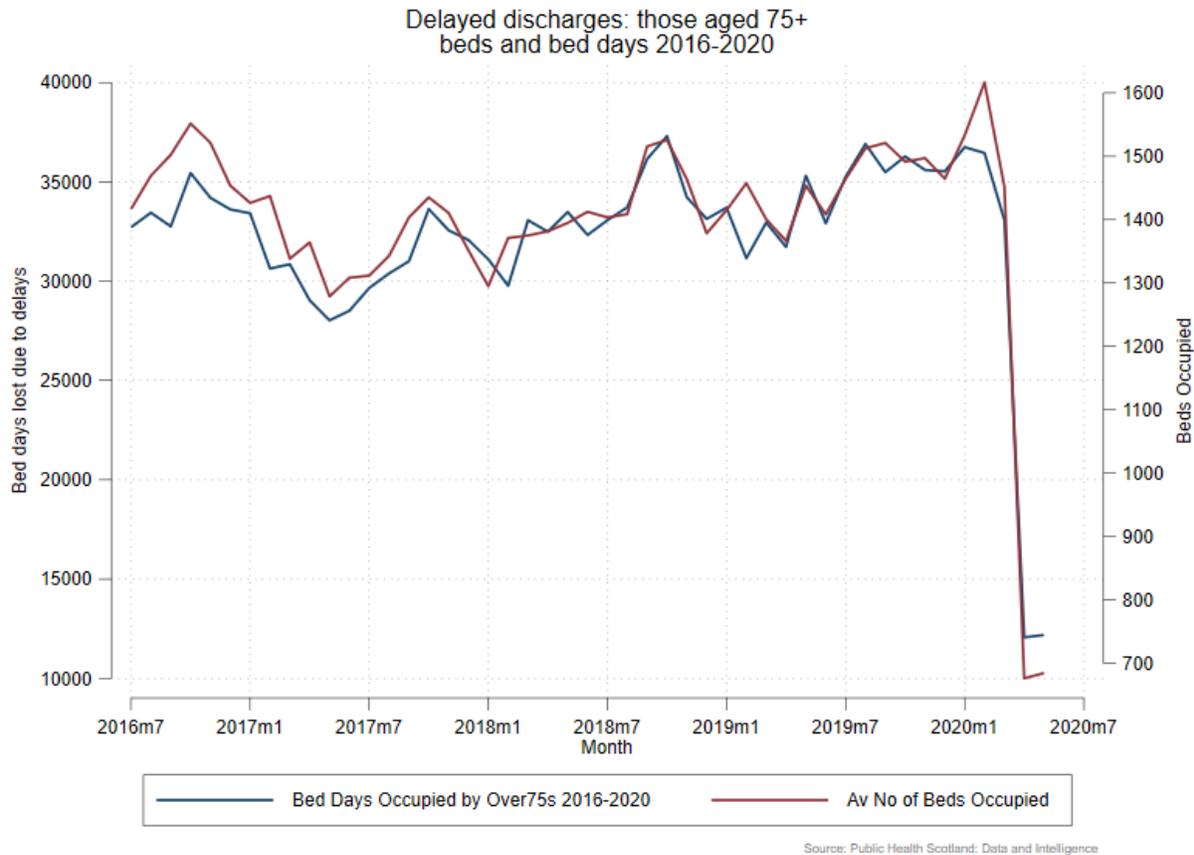
³⁷ Rojas-Garcia, A. et al (2017). Impact and experiences of delayed discharge: A mixed-studies systematic review. *Health Expectations* 21(1) pp.41-56. <https://doi.org/10.1111/hex.12619>

³⁸ House of Commons Library (2017) *Delayed Transfers of Care in the NHS*, Briefing Paper 7415, Alex Bate

³⁹See: <https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2020/07/COVID-19-and-the-production-of-statistics-2020-07-07.pdf>

⁴⁰ N.S.N. Graham, C. Junghans and R. Downes et al., SARS-CoV-2 infection, clinical features and outcome of COVID-19 in United Kingdom nursing homes, *Journal of Infection*, Available [here](#).

Figure 4: Delayed Discharges in Scotland 2016-20



Source: Public Health Scotland

The lack of similar statistics for England and Wales is disappointing. However, there is some qualitative evidence of what happened⁴¹. In mid-March, trusts were urged by NHS England and NHS Improvement to “discharge all hospital inpatients who are medically fit to leave”. On April 2, UK government guidance specified that “negative tests are not required prior to transfers/admissions into the care home”. This remained the case until April 15 when new instructions specified that all patients should be tested prior to discharge. There were capacity problems in carrying out these tests. Difficulties were compounded by the possibility of asymptomatic individuals being transferred into care homes.

3.3. The impact of COVID-19 within care homes

The emerging data and news from around the world had made it clear that older people, particularly frail older people with underlying health conditions, were at an increased risk of death from the virus. In April, worries were becoming apparent in the UK about the impact of COVID-19 on care homes and care home residents. Many charities and care bodies raised concerns about deaths of residents and those getting care at home being “airbrushed” out of

⁴¹ See: <https://fullfact.org/health/coronavirus-care-homes-discharge/>

official figures because reported deaths focussed on those occurring in hospitals⁴². Others highlighted the hidden impact of COVID-19 on care homes by looking at average mortality within care homes in comparison with previous year's death rates⁴³.

Fast forward to the end of June and there had been 54,510 deaths recorded as COVID-19 related across the UK. Of those, 17,127 (31%) had occurred within care homes and approximately 21,775 (40%) were accounted for by care home residents⁴⁴.

Understanding the factors that contributed to the devastating impact on care homes is paramount to designing system changes and policy measures to ensure the UK is prepared to cope in the event of a second wave or future pandemic. Achieving this is not without its difficulties. In particular, the recording of data and differences in care systems and practices across the UK make cross-nation comparisons difficult. Nevertheless, significant learning may result, from making such comparisons.

3.4. Share of care homes experiencing COVID-19 outbreaks⁴⁵

Comparisons of the share of care homes experiencing an outbreak across UK nations is complicated by the differing definitions of what comprises an "outbreak". There is no clear definition provided by authorities in England or Wales. In Scotland, as of the 20th July, 65% of all adult care homes had reported at least one case of suspected or confirmed COVID-19. Northern Ireland defines an outbreak as two or more cases in a facility which meet the case definition of a possible or confirmed case of COVID-19, within a 14 day period among either residents or staff in the care home". Using this definition, 37% of care homes in Northern Ireland were deemed to have been infected⁴⁶. In England, between 9th March and the 19th July, Public Health England reported that 44% of all adult care homes had reported at least one case of COVID-19⁴⁷ without defining what constitutes an outbreak. Similarly, in Wales, the definition of an outbreak has not been released by Care Inspectorate Wales. Only 33% of care homes in Wales have been reported as experiencing an outbreak⁴⁸

It is also worth pointing out that the shares reported here use 'all adult care homes' in the denominator as opposed to those care homes for older adults only. Given that older adults are at higher risk of mortality from contracting COVID-19, it is likely that many of the cases reported occurred in care homes for older adults, in which case the shares may be somewhat higher. For example, a recent study by Burton et al from 70 Scottish care homes who

⁴² See: <https://www.bbc.co.uk/news/uk-52275823>

⁴³ See: <https://www.theguardian.com/world/2020/apr/18/uk-care-home-covid-19-deaths-may-be-five-times-government-estimate>

⁴⁴ See Table 2 for details on sources.

⁴⁵ In this section, we deviate from our defined pandemic period as not all home nations provide historical weekly figures on the share of homes affected. For these reasons, we report shares up until the 19th July in England, up until the 20th July in Scotland and Northern Ireland, and up until 24th July in Wales.

⁴⁶ Department of Health, COVID-19 in Northern Ireland. 20th July report. Available [here](#).

⁴⁷ Public Health England, COVID-19: number of outbreaks in care homes - management information .Available [here](#).

⁴⁸ According to information obtained from Care Inspectorate Wales, 351 adult care homes notified of one or more confirmed COVID-19 cases up until 12 noon on 24th July

experienced COVID-19 outbreaks showed that of those, 94% came from care homes for older adults⁴⁹.

The study by Burton et al also found that the size of the care home was significantly associated with an increased risk of a COVID-19 outbreak. Moreover, a recent US study also found that care home size is significantly related to the probability of having a COVID-19 case⁵⁰. Clearly, the share of care homes reporting COVID-19 outbreaks in Scotland is much higher than the rest of the UK. However, further investigation is necessary to establish why this is the case and indeed if care home size played a role, particularly given the lower mortality figures observed in Northern Ireland with a similar distribution of care home sizes.

Although no clear causal route has been established between care home deaths and size of care home, a possible mechanism may be linked to higher staff numbers (and therefore more people entering the care homes) in larger homes. The explanation for differential shares of care homes reporting cases of suspected or confirmed COVID-19 across the home nations remains unclear.

Individual care home data, if linked with COVID-19 deaths in care homes, could be crucial to understanding the factors that might have contributed to the spread of COVID-19 within those facilities. For example, geography, staffing, ownership type etc. At the time of writing, the lowest level of geography for COVID-19 deaths within care homes that is publicly available is in Scotland, where these data are available at the Intermediate Zone. Those are 1,279 statistical geographies across the whole of Scotland, made up of between 2,500 and 6,000 household residents⁵¹. Having said this, the number of COVID-19 deaths within Intermediate Zones is likely too small to draw any strong conclusions.

3.5. COVID-19 mortality within care homes and among care home residents.

As outlined earlier in this report, in order to understand the impact of the pandemic on care home residents it is important to distinguish between deaths of care home residents within care homes and deaths of care home residents overall. Concentrating on deaths that occurred within care homes may underestimate the impact of the pandemic within the care home resident population. Table 3 below shows these differences for the UK overall and each of the UK nations. The table shows that, across the UK as a whole, 31% of all COVID-19 deaths occurred within care homes, whilst care home residents accounted for at least 40% of all UK deaths attributed to COVID-19. Deaths linked to COVID-19 amounted to 4.5% of all care home residents.

There are however, considerable differences between the four nations. In particular, in Scotland, there was a three percentage point difference in the proportion of COVID-19 deaths occurring in care homes and COVID-19 deaths overall. This may suggest that very few patients were transferred from care homes into hospital or a higher likelihood of deaths being recorded

⁴⁹ Burton et al, 2020. Evolution and impact of COVID-19 outbreaks in care homes: population analysis in 189 care homes in one geographic region. Pre-print available [here](#).

⁵⁰ Hannah et al, 2020. Characteristics of U.S. Nursing Homes with COVID-19 Case. Journal of the American Geriatrics Society. Available: <https://doi.org/10.1111/jgs.16661>

⁵¹ Source: [here](#)

as due to COVID-19 than in the other nations. It might also be due to difficulties recording usual place of residence when a death occurs in hospital. In Northern Ireland, where deaths per 100,000 were considerably lower than the rest of the UK, care home residents accounted for over half of all registered COVID-19 deaths. In comparison, the share of COVID-19 deaths accounted for by care home residents in England and Wales was far lower. Specifically, care home residents accounted for 39% of all deaths attributed to COVID-19 in England and 34% in Wales.

Table 3: Deaths of care home residents- within and out with care homes attributed to COVID-19 (weeks 11 -26)

	England	Northern Ireland	Scotland	Wales	UK
Number of COVID-19 related deaths in care homes⁵²	14,166	346	1,935	680	17,127
Number of COVID-19 related deaths of care home residents⁵³⁵⁴	18,562	423	2,094	826	21,775
Total number of COVID-19 related deaths- occurring in all locations⁵⁵	47,111	824	4,155	2,420	54,510
Share of COVID-19 related deaths within care homes⁵⁶	30%	42%	47%	28%	31%
Share of COVID-19 related deaths accounted for by care home residents⁵⁷	39%	51%	50%	34%	40%
Care home resident COVID-19 related deaths as a share of registered adult care home places⁵⁸	4.06%	2.63%	5.09%	3.23%	4.05%

As one might expect, the share of deaths occurring within care homes are broadly consistent with the differences in the share of care homes affected. In Scotland, where the share of care homes affected was highest, the share of COVID-19 deaths occurring in care homes was also

⁵² **England and Wales:** Weeks 11 to 26, ONS Deaths Registered Weekly in England and Wales, available [here](#). **Scotland:** Weeks 11-26, NRS Deaths involving COVID-19, available [here](#). **Northern Ireland:** Weeks 11-26, NISRA Weekly deaths, available [here](#).

⁵³ **England:** Weeks 11-24 from ONS Deaths involving COVID-19 in the care sector (number of deaths occurring from 2 March 2020 to 12 June 2020, registered up to 20 June 2020), available [here](#). **Northern Ireland:** Weeks 11-26, NISRA Weekly deaths, available [here](#). **Wales:** Weeks 11-24 from ONS Deaths involving COVID-19 in the care sector (number of deaths occurring from 2 March 2020 to 12 June 2020, registered up to 20 June 2020), available [here](#). **Scotland:** Weeks 11-20, NRS Deaths of Care Home Residents involving COVID-19, available [here](#) and weeks 22-26, Scottish Government COVID-19 deaths reported to the Care Inspectorate, available [here](#).

⁵⁴ As far as we are aware, there is no data for deaths of care home residents outside care homes for week 21 in Scotland

⁵⁵ All data: weeks 11 to 26, ONS Deaths Registered Weekly in England and Wales, available [here](#)

⁵⁶ Row 1 divided by row 3

⁵⁷ Row 2 divided by row 3.

⁵⁸ Row 2 divided by number of places available in adult care homes (see Table 1).

highest. Similarly, in Wales, where the share of affected care homes was lowest, the share of COVID-19 deaths occurring within care homes was also the lowest. These differences highlight the importance of protecting residents from exposure to the virus by implementing appropriate measures to prevent transmission into care homes in the first place.

The final row of Table 3 shows care home resident COVID-19 deaths as a share of all registered places in adult care homes. Once again, there is variation between the UK nations. In Northern Ireland, care home resident COVID-19 deaths accounted for under 3% of all registered older adult care home places. In Scotland, this share is closer to 5%. These figures are broadly similar to those observed in other European countries including France, Sweden, Italy, Ireland, Belgium and Spain⁵⁹.

4. Excess deaths

4.1. Measuring Excess deaths

Given the varying ways in which mortality due to COVID-19 is recorded across each of the four UK nations, the best way to make comparisons between jurisdictions is by measuring excess mortality. This is defined by the World Health Organisation as:

“Mortality above what would be expected based on the non-crisis mortality rate in the population of interest. Excess mortality is thus the mortality that is attributable to the crisis conditions.”⁶⁰

This approach avoids problematic comparisons of the effects of the pandemic arising from differences in how deaths are recorded across countries or regions and the complications that arise from differing definitions of an “outbreak” as discussed in Section 3.4. It also encompasses both direct and indirect deaths that would not have occurred in the absence of the pandemic.

In order to compare excess deaths across countries or regions with differing populations, a simple and useful statistic is the “P-Score” which is analogous to a percentage increase/decrease from a pre-defined baseline⁶¹. All the UK statistics agencies have released weekly mortality figures for the previous five years, either as an average or for each year individually as the baseline figure.

Note that though the P-Score is easily comprehensible, it does not take account of differences in variability or trends in deaths over the last 5 years such as increases due to population ageing. Thus, the P-Score does not distinguish between areas so long as the respective 5-year means are equal.

When comparing P-Scores within populations, it is important to ensure that these are calculated on a consistent basis. Thus, in relation to comparing excess deaths in care homes

⁵⁹ Comas-Herrera A, Zalakaín J, Litwin C, Hsu AT, Lemmon E, Henderson D and Fernández J-L (2020) Mortality associated with COVID-19 outbreaks in care homes: early international evidence. Article in LTCcovid.org, International Long-Term Care Policy Network, CPEC-LSE, 26 June 2020. Available [here](#).

⁶⁰ See: <https://www.who.int/hac/about/definitions/en/>

⁶¹ See: <https://www.inet.ox.ac.uk/files/6-May-20-Muellbauer-Aron-Excess-mortality-in-England-vs.-Europe-and-the-COVID-pandemic.pdf> for a wider explanation of this technique.

across the UK, it is important to be sure that a consistent definition of care homes is used in each of the home nations. This clearly depends on the definitions of care homes used by the respective inspectorates. We have tried as far as possible to maintain a consistent approach to the definition of care homes, but do not claim that there is an exact match across the four nations.

The weekly frequency of observations is useful in charting the deaths in care homes and relating that to the more general timing of deaths associated with the pandemic. However, excess deaths in some weeks may be compensated by subsequent weekly deaths that are below average. The implication is that the pandemic may have brought forward deaths that would have occurred anyway. Crucial to this calculation is the decision on the duration of the pandemic “event”. One might argue that this duration should extend until deaths return to their “normal” levels. But this must be a subjective assessment. Deaths due to unobserved causes of variation around normal levels of deaths may be wrongly assigned to the pandemic. The longer the duration, the more likely that such variation occurs. Against this effect is the pressure not to incorrectly attenuate the period during which the pandemic is deemed to be affecting mortality. We chose weeks 11-26 in 2020 as they encapsulated the week of the first UK death and the first week following this where all UK nations recorded at or below zero percentage change as shown in Figure 5.

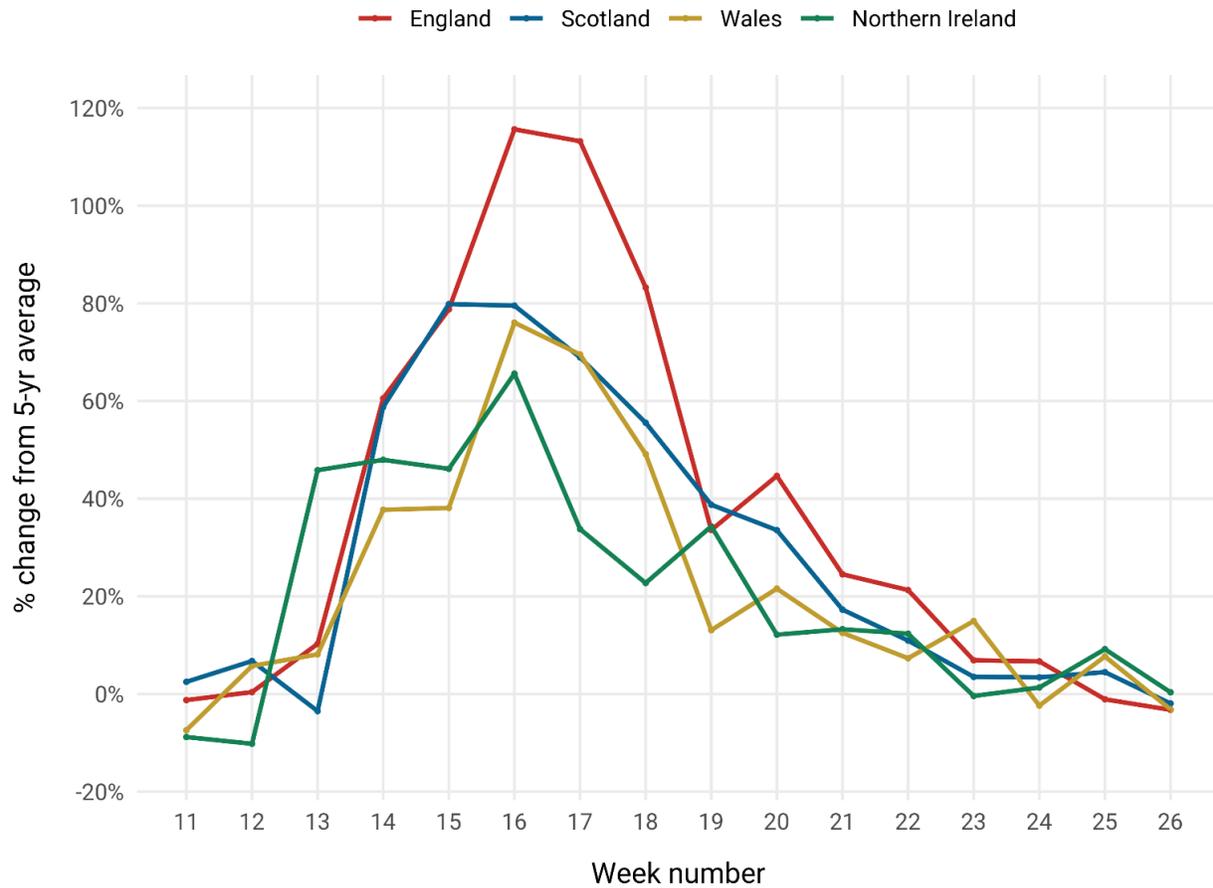
4.2. Excess deaths in the UK

Figure 5 shows England having a notably higher excess in weeks 15-18 compared to other UK countries with percentage increases of between 79% & 116% compared to the average deaths in the previous 5 years. Scotland’s highest weekly increase was 80% recorded in weeks 15 and 16 whilst the peak increase for Wales and Northern Ireland also occurred in week 16 at 76% and 66% respectively.

Figure 6 shows a breakdown of excess deaths in more detail. The overall plot shows the percentage increase (P-score) for each nation during the entire pandemic period of weeks 11-26. England’s excess is 38% higher than the average over the same period in the previous 5 years whilst Scotland, Wales, and Northern Ireland had values of 29%, 22%, and 20% respectively.

The breakdown by location of death shows startling percentage increases in care home deaths in weeks 11-26 compared to the previous 5-year average of 79%, 62%, 66%, and 46% in England, Scotland, Wales, and Northern Ireland respectively. This contrasts starkly with figures reported in the text above (Section 3.4) and in Table 3 on the percentage of care homes with COVID-19 infections and the share of COVID-19 attributed deaths compared to the number of care home residents. In both of these measures, Scotland has higher rates compared to other UK nations. Measuring excess deaths (not specifically COVID-19 deaths) shows both England and Wales to have higher rates over this period which suggests that there were differences in the way COVID-19 deaths were being registered across UK jurisdictions.

Figure 5: Weekly excess mortality in the UK. Weeks 11-26 2020. Percentage increase in mortality compared with previous 5yr average (P-Score)



Source: ONS, NRS & NISRA (provisional data). Data and code available [here](#).

Also notable in the location of death breakdown in Figure 6 is the juxtaposition of increases in deaths at home (broadly consistent across nations) with virtually no change in hospitals (except in England which recorded only a relatively small increase of 19%). This is despite almost half of all COVID-19 related deaths occurring in hospitals across all jurisdictions. This provides further evidence of a displacement of deaths that would “normally” have occurred in hospital to the community setting either at home or in care homes. The lack of data available on domiciliary social care means no analysis on the impact of the higher rate of deaths at home on this sector is currently possible.

Figure 6: Excess mortality in the UK. Weeks 11-26 2020 (breakdown).



Source: ONS, NRS & NISRA (provisional data). Data and code available [here](#).

Deaths in “Other” settings, such as jails, vary only by small amounts reflecting the relatively small numbers of deaths that occur in these locations.

The final breakdown, by location and week, highlights the large increases particularly experienced by care homes at the peak of the pandemic likely reflecting increases in both COVID-19 and non-COVID-19 deaths. Week 17 saw a 253% increase in deaths in care homes compared to the average of the previous 5-years in England (an excess of 5,440 deaths). The increase in Scotland for the same week was 179% (441 excess deaths), and in Wales 205% (217

excess deaths). The peak in excess deaths in care homes in Northern Ireland occurred one week earlier in week 16 where a 187% increase was recorded (97 excess deaths). The impacts on the management of care homes where COVID-19 outbreaks or a large number of non-COVID-19 deaths occurred at a time when staff shortages due to illness were likely to have been severe. This potential management breakdown should be a priority in planning and preparation for any future second-wave of COVID-19.

Relevant to this discussion is the study by Burton et al⁶² in the NHS Lothian region in Scotland (undergoing peer-review) where no excess deaths were recorded in care homes that did not experience a COVID-19 outbreak. Furthermore, a quarter of all COVID-19 related care home deaths occurred in just 2.6% of care homes included in the study and a half of COVID-19 deaths occurred in 6.9% of included homes. This is early research but indicates a full understanding of the mechanisms behind deaths in care homes in the UK will take time, better data, and in-depth knowledge of the sector.

5. Testing in the UK nations

The implementation of a comprehensive, mass testing strategy that aims at detecting asymptomatic and pre-symptomatic transmission is considered one of the most effective disease control tools available in the absence of a vaccination program, especially in high-risk environments such as care homes.⁶³

The UK nations are currently recognising the fundamental role played by care home staff and residents that present mild or no symptoms and the importance of systematic testing. However, regular testing is a recent strategy and testing practices and guidelines have been changing since the end of February.

The scientific community has been suspecting since February that asymptomatic or pre-symptomatic transmission may play a considerable role in spreading the virus, especially in high-risk environments such as care homes. A journal article published in June reviewed the evidence and suggested that 40-45% of infections within communities may be due to people with no symptoms.⁶⁴ A study published on 24th April documented events at a skilled care

⁶² Burton JK et al (preprint) Evolution and impact of COVID-19 outbreaks in care homes: population analysis in 189 care homes in one geographic region <https://www.medrxiv.org/content/10.1101/2020.07.09.20149583v1.full.pdf>

⁶³ See, among the many contributions:

- <https://www.theguardian.com/commentisfree/2020/apr/01/lockdown-buys-time-virus-mass-testing-coronavirus-uk>,
- <https://roadmap.paulromer.net>.
- <https://www.technologyreview.com/2020/04/28/1000671/covid-tests-millions-per-day-crispr-biotechnology-advances/>

For care homes see:

- <https://www.ecdc.europa.eu/sites/default/files/documents/covid-19-long-term-care-facilities-surveillance-guidance.pdf>
- https://www.who.int/publications/i/item/WHO-2019-nCoV-Policy_Brief-Long-term_Care-2020.1
- the numerous posts on the LTC COVID website, e.g.: <https://ltccovid.org/2020/04/18/the-problem-of-asymptomatic-positive-infections-among-care-home-staff-and-residents-emerging-evidence-and-implications/>

⁶⁴ Horan and Topol (2020) provide an excellent review and limitations of the existing body of evidence listing a few known case studies: <https://www.acpjournals.org/doi/10.7326/M20-3012>. An updated list of case studies compiled by Sarah House and

facility in the State of Washington, USA. It illustrated that the standard measures adopted by the facility (e.g., isolation of residents with symptoms, use of protective equipment and temperature checks) did not stop the transmission. The CDC carried out tests for 76 out of 89 residents soon after the outbreak. About three weeks after the virus was introduced, they found that 48 residents (63%) tested positive. Of these 48, 27 (56%) were asymptomatic at the time of testing; 24 subsequently developed symptoms. About a month after the first cases were identified, 15 (17%) of the 89 residents had died.

A more recent epidemiological study conducted in the UK confirms the high proportion of asymptomatic transmission in such settings (Graham et al. 2020). The researchers tested and re-tested 394 residents of four London care homes that experienced large outbreaks and found that 43% of the confirmed cases were asymptomatic at the time of the test.⁶⁵

An international systematic review has found that systematic screening of care home residents shows that as many as 75% of residents and up to 100% of staff were found to be asymptomatic at the time of testing⁶⁶.

In the UK, testing capacity and eligibility for the *whole population* were very restricted initially and had been expanded during the crisis to cover more categories of people, but not before mid-April. Testing practices have been characterised by difficulty with the expansion of capacity and achievement of targets in all four nations. There were also widespread complaints about a lack of access to the testing capacity that was available.⁶⁷

The statistics communicated daily by the UK Government on testing were also criticised by the UK Statistics Authority as “far from complete and comprehensible”. The criticism was based on the norm of combining tests carried out with tests posted out (and not yet and maybe never processed) and the lack of distinction between total number of tests and people tested.⁶⁸

At the end of February, testing was limited to people who had symptoms after returning from a country with an outbreak and to patients in hospitals with flu-like symptoms. Contact tracing was abandoned nationally on 13th March. At that time, the testing effort was directed towards patients in hospitals, and later towards NHS staff. However, by the end of April, testing eligibility for the whole population expanded to include everyone with symptoms (in Scotland and Northern Ireland tests are not available for children up to 5 years of age). Priority testing was also made available for essential workers, including care home workers. The effort to expand testing was accompanied by confusion in communicating the actual number of tests carried out. This criticism was common across all nations.

As of August, coronavirus tests for the whole population are mainly available for those with symptoms and explicitly exclude pre-symptomatic and asymptomatic cases in every country of

Eric Fewster can be retrieved on the LTC COVID website at the following link: <https://ltccovid.org/2020/06/12/asymptomatic-and-pre-symptomatic-transmission-in-uk-care-homes-and-infection-prevention-and-control-ipc-guidance-an-update/>

⁶⁵ <https://www.medrxiv.org/content/10.1101/2020.05.19.20105460v1>

⁶⁶ Salcher-Konrad M, Jhass A, Naci H, Tan M, El-Tawil Y, Comas-Herrera A. COVID-19 related mortality and spread of disease in long-term care: a living systematic review of emerging evidence. *medRxiv*. 2020. doi:10.1101/2020.06.09.20125237.

⁶⁷ <https://www.theguardian.com/world/2020/aug/24/coronavirus-home-test-kits-run-out-in-england-and-scotland>

⁶⁸ <https://uksa.statisticsauthority.gov.uk/correspondence/sir-david-norgrove-response-to-matt-hancock-regarding-the-governments-covid-19-testing-data/>

the UK. The only exception is staff and residents of care homes. At least in principle, each country is currently committed to regular testing of all staff and residents, whether they present symptoms or not.

Testing was initially available in NHS hospitals only. The effort to scale up testing capacity since April was accompanied by the establishment of drive- and walk through test sites, and mobile testing units to improve testing of key workers.

In summary, each country has followed broadly similar testing strategies -- a conclusion that applies also to testing in care homes.⁶⁹ The approach to testing in care homes of staff and residents have been characterised by controversy since March, with respect to hospital discharges, treatment and testing of asymptomatic residents and staff, and importantly to actual availability of tests to meet targets. The constant changes to guidelines created some confusion.

Across the four nations, the period from March to end of April has been characterised by a focus on testing of residents and symptomatic care home staff, while the period between mid-May to August by a focus on testing of all staff and residents -- including asymptomatic cases -- and since July to a commitment to regular systematic testing and re-testing.

The next section describes the development of testing strategy in care homes in more detail.

5.1. Testing of care home residents and staff

The evolution of testing practices and related recommendations for care homes seems to indicate that each country put little emphasis on the asymptomatic or pre-symptomatic transmission during the peak of the crisis and until mid-April.

There are four main guidelines that relate to testing of residents, two of which relates to hospital discharges.⁷⁰

On 25th February the *Guidance for social or community care and residential settings on COVID-19*⁷¹ reflected the view that, at that time, there was no virus transmission within the community. The guidance did not mention testing and did not recognise asymptomatic transmission, while establishing that:

- “If the staff, member of the public or resident has not been to specified areas in the last 14 days, then normal practice should continue” (section 8).

⁶⁹ It is not clear whether the constitutive countries were posting separate and distinct guidelines on before mid-April. For instance the dates of first publications for the main Guidelines in Scotland and Northern Ireland is 26 April. For Scotland see https://hpspubsrepo.blob.core.windows.net/hps-website/nss/2980/documents/1_covid-19-information-and-guidance-for-care-homes.pdf (page 1) and for Northern Ireland: <https://www.health-ni.gov.uk/publications/covid-19-guidance-nursing-and-residential-care-homes-northern-ireland>

⁷⁰ See, e.g., <https://nhsproviders.org/media/689548/spotlight-on-recent-discharges-into-care-homes-nhs-providers.pdf> and <https://www.bbc.co.uk/news/52674073>

⁷¹ <https://www.gov.uk/government/publications/guidance-for-social-or-community-care-and-residential-settings-on-covid-19/guidance-for-social-or-community-care-and-residential-settings-on-covid-19>

- “It remains very unlikely that people receiving care in a care home or the community will become infected” (section 7).

Tests were conducted on residents who showed symptoms, and “typically ceased after two to five cases were positive” ⁷².

This guideline was followed by a Guidance on hospital discharges into care homes (*COVID-Hospital Discharge Service Requirements and Guidance on Admission and Care of Residents during COVID-19 Incident in a Care Home*) that was regularly updated.

The first one on 19th March did not detail any specific requirements about testing patients discharged from hospitals. ⁷³

On 2nd April a new guidance intended for care homes (*Admission and Care of Residents during COVID-19 Incident in a Care Home*) recommended providing care in isolation for residents discharged from hospitals with a positive COVID-19 test. However, it overlooked the potential risk from asymptomatic transmission by establishing that if a resident had no symptoms of COVID-19 upon discharge, the care home should provide care as normal. ⁷⁴

On 15th April a new action plan (*COVID-19: Our Action Plan for Adult Social Care*) changed the recommendation drastically. The new guidelines recognised the importance of asymptomatic transmission by committing to:

- Test all symptomatic residents
- Test and all admissions to care homes, whether symptomatic or not, starting with patients discharged from hospitals
- Isolate all admitted residents whether symptomatic or asymptomatic and those waiting for a test result

These guidelines were superseded and regularly updated by specific documents published by each country. For instance, in Wales the announcement that symptomatic care home residents, and those returning from hospital, were all being tested came on 22nd April.

Care home staff could apply for a test if they had symptoms after their category was added to the list of essential workers in April across the countries. Care home staff could also apply for a test if a member of their household presented COVID-19 symptoms. Northern Ireland expanded testing for care home workers in early April. The first Northern Ireland staff testing site from the UK-wide initiative commenced on 4th April whereby testing was available for healthcare staff. In Wales, testing was made available to symptomatic care workers if they or their families had symptoms from 18th April.

⁷² See p. 9 <https://www.medrxiv.org/content/10.1101/2020.07.09.20149583v1>

⁷³ See https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/880288/COVID-19_hospital_discharge_service_requirements.pdf. Legal experts highlighted that the guidance was also missing details “whether a care home can be compelled to accept the discharge of a patient that has tested positive for COVID-19 head on”. This issue would be finally solved on 15th April. See, e.g.: <https://www.ridout-law.com/admitting-service-users-into-care-settings-during-the-covid-19-crisis-what-does-the-guidance-say/>

⁷⁴ See <https://www.northamptonshire.gov.uk/coronavirus-updates/Documents/covid-19-care-homes-guidance.pdf>

By the end of May, the focus shifted towards the virus transmission of asymptomatic cases and, between then and July, the Governments of the four nations pledged to extend testing towards both asymptomatic residents and care home staff.

In Wales, from 2nd May, all residents and staff in care homes with outbreaks or those with at least 50 beds were being tested. From 16th May tests were available to all care home staff and residents and on 18th June it was announced that all registered adult care homes had been offered testing and that testing was almost complete.

On the 13th May the Health Minister on Northern Ireland outlined three priority areas to protect care home residents, one of which was to significantly expand testing in care home residents and staff. This expansion was aided by The Northern Ireland Ambulance Service who provided a mobile testing service for care homes and additional nurses from the HSC were deployed to support testing in care homes. On 18th May the Health Minister announced that Covid-19 testing will be made available to all care home residents and staff across Northern Ireland with the intention to complete the roll-out of testing to all residents in the next month. During this time, care home staff and families could access testing if they have symptoms and all staff and residents are also tested in homes when two or more cases (staff or residents) have symptoms.

Following health official warnings that care home workers were the main vector of disease, the focus shifted towards the importance of regular testing of care home staff. For instance, England and Scotland announced their plan to routinely testing care home workers in mid-May.⁷⁵ On 3rd July, the Department of Health and Social Care published results from a survey on the impact of coronavirus in care homes, The Vivaldi Study.⁷⁶ The study surveyed some 9,000 care homes in England between 26th May to 19th June and researchers analysed the responses of about 5,000 care homes identifying potential risk factors such as the prevalence of infection in staff and the practice to use agencies.

This new evidence supported the roll-out of regular testing (retesting) that started in England on 6th July. Retesting involves testing all residents every 28 days and staff every week. The same strategy has been adopted by Scotland around the same time⁷⁷ and on 3rd August by both Wales and Northern Ireland.⁷⁸

The pledge to regular testing and retesting in care homes across the four nations seems ambitious. Given that the testing strategy has been characterised by lack of capacity and unmet targets, doubt remains as to whether this strategy can deliver as promised. Recent reports seem to indicate that capacity issues have hampered and still hamper the system, with delays in testing kits, and in getting back the results. As a consequence, even when guidelines started recognising

⁷⁵ <https://www.thecourier.co.uk/fp/news/politics/scottish-politics/1322608/care-home-staff-to-be-repeatedly-tested-for-covid-19-as-officials-say-they-were-primary-vectors-for-spread-of-virus/>

⁷⁶

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

⁷⁷ <https://www.gov.scot/news/enhanced-safety-for-health-and-social-care-staff/>

⁷⁸ In Wales and Northern Ireland have pledge to test staff every two weeks instead of every week, see: <https://www.health-ni.gov.uk/news/rolling-testing-programme-care-homes> (accessed 24 August) and <https://gov.wales/testing-process-care-homes-covid-19-html> (Accessed 21 August)

the importance of testing, they may not have been consistently implemented by Health Boards.⁷⁹ A series of Freedom of Information Requests show that some Health Boards in Wales tested between 29% to up to 60% of discharged patients after the guidelines recommended to test everyone in the second half of April. One Health Board tested as little as 6.8%.⁸⁰

A robust assessment of the implementation of testing in care homes and infection rate has been challenging, given the current constant changes of practices, targets, and the lack of consistent and comparable data across the four nations. The next section provides information on the data collected by different nations, their sources, and highlights current limitations.

5.2. Testing data

Data on testing in the UK is available at the UK dashboard [here](#). It provides daily and cumulative figures of tests carried out over time. The data reported cannot distinguish between tests processed and people tested and as a consequence it may include multiple tests for an individual. There is no systematic collection of data concerning care homes at the UK level.

England

In England, The Department of Health and Social Care publishes weekly updates on people tested, and the share tested positive from 28th May. These data and corresponding report are available [here](#). Data before 28th May can be found [here](#) but are not directly comparable to the latest figures.

There seems to be no systematic reporting of testing of residents or staff in care homes, which makes it impossible to assess whether targets described in the previous sections are met.

Wales

In Wales, testing data is published weekly by the Welsh Government. The publication includes specific tables on number of tests recorded for care home residents and staff from the week commencing 16th March. The figures reported cannot distinguish between tests processed and people tested. There is also a substantial number of tests conducted in non-NHS Wales labs that cannot distinguish between staff or residents (i.e., they can be referring to either). The report and data can be found [here](#). The data shows that the number of tests has increased since the end of June. Over the last three weeks of data available (from 27th July to 10th August), the NHS Wales conducted an average of about 9,000 tests per week on staff with a positivity rate of 0.1%. Over the same period an average of 1,800 tests per week were carried out on residents (down from a peak of 5,400 weekly tests at the beginning of June). The positivity rate is 0.1%. The non-Wales labs – that cannot distinguish between staff and residents -- have been processing a larger number of tests since the end of June; their weekly average is about 13,000 tests with a positivity rate of 0.2%. Given the limitations highlighted, it is hard to assess how close Wales is to the current targets of regular testing every 28 days for residents and every two weeks for staff.

⁷⁹ <https://inews.co.uk/news/uk/care-homes-testing-coronavirus-matt-hancock-569268>

⁸⁰ <https://www.walesonline.co.uk/news/politics/care-home-coronavirus-discharge-covid-18714791>

Northern Ireland

In Northern Ireland, the Department of Health provides daily updates on the number tests conducted and the share of positive cases for the whole population. This data is available in the online dashboard [here](#). Historical data are also available [here](#).

There seems to be no systematic reporting of testing in care homes.

Scotland

In Scotland, the Scottish Government reports weekly data on testing of care home staff and residents split by care homes with confirmed COVID-19 and without confirmed COVID-19, broken down by NHS boards. The data can be found [here](#). Weekly statistics are available from the week commencing 15th June but the time series is not comparable until 16th July due to changes in reporting cycle. The weekly tables are missing the number of positive cases, which are presented for residents only in the daily update for [Scotland](#). Over the last three weeks of data available, from 24th July to 13th August, a weekly average of over 35,000 care workers and 1,500 residents have been tested in care homes with no confirmed case. Given the recent lower infection rate in the community, the number of tests processed are smaller for care homes with confirmed cases over the same period: the weekly average is 680 tests for staff and 100 for residents. Given the lack of systematic reporting of positive cases, it is hard to say anything about positivity rates and distance from current testing targets.

5.3. Alternative approaches to testing

As mentioned, the current testing regime appears ambitious. An alternative surveillance strategy put forward by the European Centre for Disease Prevention and Control (ECDC) aims at trading off the need to test comprehensively and regularly with the reality of testing capacities.⁸¹ The recommendations crucially depend on the level of infection in the local area, and they differ between facilities with confirmed cases vs no cases in affected vs unaffected regions. According to this strategy, the surveillance systems in care homes should be based on surveillance at the community level, focussing the shift towards testing all the staff regularly in affected areas (rather than all staff and residents everywhere all the time). The guidelines emphasise the importance of updated transmission of data from the local area to care homes and vice-versa.

To appreciate the extent of the ECDC guidelines for care homes we summarise their recommendations in Table 4.⁸²

Further, testing capacity can be increased substantially by adopting innovative measures such as pooling/group testing and/or saliva-based testing. Pool testing reduces the costs as only defined groups are tested. Only if the test comes back positive, each member of the pool is

⁸¹ <https://www.ecdc.europa.eu/sites/default/files/documents/covid-19-long-term-care-facilities-surveillance-guidance.pdf>

⁸² This is an extract of Table 2 in the ECDC document on Surveillance in care homes:

<https://www.ecdc.europa.eu/sites/default/files/documents/covid-19-long-term-care-facilities-surveillance-guidance.pdf>

tested individually.⁸³ Early trials seem to validate the strategy at least in relatively small groups.⁸⁴ Epidemiologists and public health scientists are engaged towards experimenting, scaling up and adopting quick testing as a disease control mechanism in different settings such as Universities that could be adopted in care homes.⁸⁵

Scenario in care homes	Testing of residents	Testing of staff
No cases	<p>Affected area: random samples, dependent on testing capacities</p> <p>Unaffected area: dependent on national testing policy for LTCFs.</p>	<p>Affected area: consider comprehensive testing for all staff weekly/biweekly*</p> <p>Unaffected area: dependent on national testing policy for LTCFs or random samples.</p>
≥1 possible case	As soon as possible, test at least all possible case(s).	As soon as possible, test all possible case(s), optimal: comprehensive for all staff.
≥1 confirmed case	Comprehensive testing of all residents including those who have died, dependent on testing capacity	Comprehensive testing for all staff, test regularly (weekly-bi-weekly) if possible.

Finally, a system of surveillance and testing in care homes needs also to be accompanied by data on infections at community and hospital level. For instance, the initial lack of guidelines addressing testing and the information gaps related to hospital discharges created confusion and controversy and it is now at the centre of a media attention across the four nations.⁸⁶ As noted in other parts of this report, data is vital to inform policies and build an effective disease control strategy.

⁸³ <https://jamanetwork.com/journals/jama/fullarticle/2764364aliva-based>

⁸⁴ <https://theconversation.com/group-testing-for-coronavirus-called-pooled-testing-could-be-the-fastest-and-cheapest-way-to-increase-screening-nationwide-141579>

⁸⁵ <https://twitter.com/CTHerman/status/1296872182698606595>

⁸⁶ For instance, see:

- In Scotland: <https://www.sundaypost.com/fp/critics-question-boards-secrecy-over-transfers/>
- In Wales: <https://www.southwalesargus.co.uk/news/18613128.study-gwent-care-homes-covid-19-risk-hospital-patients/>
- In England: <https://www.bbc.co.uk/news/uk-england-stoke-staffordshire-53005414>, <https://www.dailymail.co.uk/news/article-8510031/NHS-hospital-Bristol-discharged-213-untested-patients-20-Covid-19-care-homes.html>
- In Northern Ireland: <https://www.belfasttelegraph.co.uk/news/health/coronavirus/returning-covid-19-patients-to-care-homes-slammed-39420855.html>

6. COVID-19 and long-term care at home

The focus of this report has been on the impact of COVID-19 within care homes and amongst care home residents. Similarly, most media reports throughout the pandemic have also focused on care homes. Clearly, the impact of COVID-19 in this setting has been devastating across the whole of UK and therefore the focus on care homes is appropriate.

Having said that, care in the community comprises a large share of all LTC for adults. Of particular importance amidst the backdrop of the COVID-19 pandemic, are those older adults who live at home and receive LTC within their homes, often with underlying chronic health conditions. Of course, their needs are likely to be somewhat lower than older individuals who receive care within a care home, but nonetheless, many are frail and would be at higher risk of contracting and subsequently not surviving COVID-19.

In Scotland, the latest figures available from the Social Care Survey (2017/18) showed that 47,070 people aged 65+ received a personal care service in their own home⁸⁷. That is around 14,000 more individuals than the estimated number living in care homes for older adults for the same period⁸⁸. These figures demonstrate that of all older adults receiving LTC in Scotland, nearly 60% receive it within their own homes. This may reflect the lower average need of LTC clients in the community but could also reflect social care policy shifts over the last decade, which have encouraged displacement from care homes and hospitals into private homes. In Scotland, for example, the Health and Social Care Delivery Plan⁸⁹ has placed emphasis ‘shifting the balance of care’ and specifically supporting frail older people to stay in their own homes for as long as possible. These shifts are similar throughout the UK.

At the time of writing, there is limited evidence on the impact on COVID-19 on those receiving social care services in their own homes. It has attracted little research or media attention. As far as we are aware, England is the only UK nation to publish data on COVID-19 cases for those receiving care at home (or domiciliary care). These data come from reports made by providers to the Care Quality Commission. The most recently published data cover the period 10th April 2020 to the 12th June 2020⁹⁰. During this period, 3,628 excess deaths of domiciliary care recipients were reported. Amongst these, only were registered as 819 involving COVID-19. The large number of excess deaths that are not reported as being linked to COVID-19 remain completely unexplained. It is not clear whether these deaths are unrecorded COVID-19 deaths or if they are deaths that are indirectly linked to the pandemic. For example, access to health care and delivery of care services may have been impacted by staffing shortages. A recent report from the Health Foundation⁹¹ also noted that non-COVID-19 deaths among those receiving home care were rising well before the 10th April and that the overall proportional increase in deaths is greater in the domiciliary setting compared to care homes. The Health

⁸⁷ Scottish Government, Free Personal and Nursing Care, 2017/18. Available [here](#).

⁸⁸ Estimated number of care home residents in care homes for older adults in 2017 was 32,691. See Table 1.

⁸⁹ Scottish Government, 2016. Health and Social Care Delivery Plan. Available [here](#).

⁹⁰ ONS, Deaths involving COVID-19 in the care sector, England and Wales: deaths occurring up to 12 June 2020 and registered up to 20 June 2020 (provisional). Available [here](#).

⁹¹ Hodgson et al, 2020. Briefing: Adult social care and COVID-19 Assessing the impact on social care users and staff in England so far. Available [here](#).

Foundation report also pointed out that deaths reported by the Care Quality Commission are likely to underestimate actual deaths for several reasons, including their exclusion of data from self-employed or unpaid carers.

For Wales, information provided by Care Inspectorate Wales shows that around 20% of Domiciliary Support Services notified of one or more confirmed COVID-19 cases between the start of the COVID-19 outbreak and 24th July (numbers affected are not available).

In addition to those receiving care at home from formal, paid carers, it is widely recognised that unpaid carers make up a significant proportion of the overall provision of LTC at home. Emerging evidence on unpaid carers suggests that their responsibilities have increased due to a number of effects of the pandemic, including loss of access to other services such as respite and day care⁹².

Overall, the limited evidence that is circulating surrounding LTC at home clearly highlights the importance of understanding how COVID-19 has affected those LTC service users who receive care at home, both in terms of mortality, but also in terms of health and well-being. However, the significant lack of data across the whole of the UK makes this an impossible task.

7. Discussion and conclusion

The experiences across the whole of the UK demonstrate the devastating impact that COVID-19 has had within the LTC sector. Specifically, care home residents have been particularly vulnerable to experiencing fatal COVID-19 infections.

In this report, we have attempted to collate, as far as possible, publicly available data that are comparable across each of the four UK nations in order to inform the understanding of the impact of COVID-19 within the LTC setting.

Overall, care home residents accounted for 40% of all COVID-19 registered deaths in the UK. At the same time, despite having broadly similar LTC settings, there are differences between the four UK nations. In Northern Ireland, where weekly deaths per 100,000 remained lower than any other nation throughout the pandemic period, care home residents accounted for 51% of all COVID-19 deaths. In contrast, in Wales care home residents accounted for 34% of COVID-19 deaths. Such comparisons like these depend on the assumption of consistent and comparable recording practices between the four jurisdictions, which are difficult, as yet, to validate.

A further metric that we have presented to make such comparisons is that of excess mortality as the percentage increase over average historic deaths. Using this measure, we find that over our defined pandemic period England had a 38% increase in mortality compared to 29% in Scotland, 22% in Wales, and 20% in Northern Ireland. Using the same metric also revealed that, during the pandemic, care homes experienced higher rates of excess mortality compared to any other setting. In particular, there was a 79% increase in mortality over the pandemic period in English care homes compared to 62% in Scotland, 66% in Wales, and 46% in Northern Ireland.

⁹² Lorenz-Dant K. (2020) International examples of measures to support unpaid carers during the COVID-19 pandemic Report in LTCcovid.org, International Long-Term Care Policy Network, CPEC-LSE, 17 June 2020.

The deaths of care home residents registered as COVID-19 amounted to just over 4% of all registered care home beds in the UK (4.1 in England, 2.6 in Northern Ireland, 5.4 in Scotland and 3.2 in Wales). Excess deaths in care homes were equivalent to 5.5% of all beds (5.5 in England, 2.5 in Northern Ireland, 6.3 in Scotland and 4.2 in Wales).

In Scotland, recent evidence shows that in homes where there was no COVID-19 outbreak, there was also no excess mortality⁹³. Whilst this result is perhaps intuitive, it is also promising in the sense that it potentially shows that the introduction of lockdown measures has not had an adverse impact on care home resident mortality. However, that is not to say that the mental health and wellbeing of care home residents were not impacted as a result of the measures. At the same time, it does not rule out the possibility that excess mortality in care homes where there were outbreaks, was attributed to both COVID-19 and lockdown measures. A recent report by the Department of Health and Social Care and others, predicted that there had been 10,000 non-COVID-19 excess deaths among care home residents⁹⁴. This is certainly an area warrants further investigation.

A key next step in the analysis of COVID-19 mortality within care homes will be to understand if there are specific care home characteristics that have led to some homes experiencing worse outbreaks and mortality rates than others. For example, recent evidence and figures suggest that care home size contributes to the likelihood of a home experiencing an outbreak⁹⁵. This is understandable in the sense that larger care homes have more potential routes by which infection may be passed on. Similarly, one would expect infection to be more likely in care homes when the level of infection in the surrounding area is high.

Whether ownership type is related to infection rate is not clear from the data available thus far. Answering this question is challenging since ownership models vary widely, particularly in the private sector.

The dramatic increase in discharges of patients from hospital into the community at the beginning of the pandemic may have played a role in the spread of COVID-19 into care homes. Initial guidance urged that patients be transferred without a need for testing. However, establishing this link is extremely difficult, because data limitations mean that it is extremely difficult ex post to establish whether care home residents received a community infection or one that could be linked to a hospital outbreak.

Lack of accurate, timely data has been an impediment to improving outcomes for individuals receiving LTC during the COVID-19 pandemic. The UK and devolved governments were aware of data deficiencies before the pandemic. Just this year, the Office for Statistical Regulation (OSR) published two reports on the state of adult social care statistics in England and Scotland⁹⁶. Both

⁹³ Burton et al, 2020. Evolution and impact of COVID-19 outbreaks in care homes: population analysis in 189 care homes in one geographic region. Pre-print available [here](#).

⁹⁴ Department of Health and Social Care, Office for National Statistics, Government Actuary's Department and Home Office. Direct and Indirect Impacts of COVID-19 on Excess Deaths and Morbidity, 15 July 2020. Available: [here](#).

⁹⁵ Hannah et al, 2020. Characteristics of U.S. Nursing Homes with COVID-19 Case. Journal of the American Geriatrics Society. Available: <https://doi.org/10.1111/jgs.16661>

⁹⁶ Office for Statistical Regulation, January 2020. Report on Adult Social Care statistics in England, available [here](#). Report on Adult Social Care statistics in Scotland, available [here](#).

reports highlighted the evident imbalance between funding for health care statistics versus that of social care and the pressing need to address this imbalance. A need that has been exposed further by COVID-19.

Whilst the OSR could not have predicted the imminent onset of COVID-19 after publishing their reports, addressing some of the key data gaps they identified could have proved extremely useful in assisting our understanding of the impact of COVID-19 in various avenues of the LTC setting.

Our report has also argued that there is a lack of data on individuals who receive care at home and on those who have their own care arrangements e.g. via an unpaid carer or through purchasing their own care. In terms of those arranging their own care, Department for Work and Pensions data on disability benefits, like Attendance Allowance and Disability Living Allowance, might facilitate understanding of individuals' choices in purchasing care.

Another data gap that has surfaced because of the pandemic concerns data on the discharging of patients from hospital to other settings. Though most of the UK jurisdictions regularly collect components of this data, the pandemic has highlighted its inability to identify individuals entering care homes from hospital. Worryingly the onset of the pandemic in England and Wales resulted in a complete halt to the collection of delayed transfer of care data.

The current testing regime is based on regular systematic testing of staff and residents recognises the importance of asymptomatic transmission of residents and staff. However, alternative approaches in which testing depends on the local infection rate and the adoption of innovative of pool testing should be considered – given the lack of testing capacity that affected some areas.

Furthermore, though the respective UK nation's statistical authorities have been publishing broadly comparable COVID-19 related mortality data for care homes and care home residents, the lack of individual, care home level data on COVID-19 related mortality limits our ability to draw conclusions surrounding care home characteristics and COVID-19 outbreaks. This data would provide invaluable information for future planning.

In conclusion, the COVID-19 pandemic has had devastating consequences throughout the UK. Unfortunately, in terms of mortality, those consequences have disproportionately affected adults who receive LTC in care homes. Those adults are often the oldest old in society and have substantial care needs. The data presented in this report unquestionably demonstrate the complexity of the situation. We find that despite having very similar populations, LTC policy and service provision, there are notable differences in COVID-19 mortality and outcomes within this setting, between the home nations. Several questions remain unanswered: the role of delayed discharges and transmission; links between care home characteristics and outbreaks; care at home and the impact of COVID-19 on care recipients and carers, to name but a few. The pandemic has acutely exposed the need for the timely and accurate collection of better quality social care data. Without such data, our ability to prevent a repetition of the traumatic effects of the pandemic on LTC recipients is limited.

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The authors alone are responsible for the interpretation of the data and any views or opinions presented are solely those of the author and do not necessarily represent those of the aforementioned bodies.

Table A: Comparable COVID-19 mortality data within the UK

Nation	Source	Recording of COVID-19 mortality	Recording of weeks	Pandemic onset (i.e. first COVID-19 death)	Breakdown by location of death	Breakdown by gender and age	Breakdown by location, age and gender
England	Office for National Statistics (ONS)	ICD-10 U07.1 and U07.2	Week 1 is week ending Friday 3 rd January 2020	Week 11 (w/c 7 th March)	From Week 11 onwards: Locations: Care home; Elsewhere; Home; Hospice; Hospital; Other communal establishment	England and Wales only ⁹⁷ Age bands: <1;1-4;5-9;10-14;15-19;20-24;25-29;30-34;35-39;40-44;45-49;50-54;55-59;60-64;65-69;70-74;75-79;80-84;85-89;90+	Yes (care home residents). Age bands: 0-64;65-69;70-74;75-79;80-84;85-89;90+. By date of occurrence ⁹⁸ .
Northern Ireland	Northern Ireland Statistics and Research Agency (NISRA)	ICD-10 U07.1 and U07.2	Week 1 is week ending Friday 10 th January	Week 11 (w/c 14 March)	From Week 11 onwards: Locations: Hospital; Care Home; Hospice; Home; Other	Yes Age bands: <7 days;>7 days and < 1 year;1-14;15-44;45-64;65-74;75-84;85+	No
Scotland	National Records of Scotland (NRS)	ICD-10 U07.1 and U07.2	Week 1 is week commencing Monday 30 th December 2019	Week 12 (w/c 16 th March)	Yes Locations: Hospital; Care Home; Home/other non-institution; Other institution	Yes Age bands: <1;1-4;5-9;10-14;15-19;20-24;25-29;30-34;35-39;40-44;45-49;50-54;55-59;60-64;65-69;70-74;75-79;80-84;85-89;90-94; 95+	Yes (Age bands- Under 1 year; 1-14;15-44;45-64;65-74;75-84;85+)
Wales	Office of National Statistics	ICD-10 U07.1 and U07.2	Week 1 is week ending Friday 3 rd January 2020	Week 12 (w/c 14 th March)	Yes Locations: Care home; Elsewhere; Home; Hospice; Hospital; Other communal establishment	England and Wales only ⁹⁹ Age bands: <1;1-4;5-9;10-14;15-19;20-24;25-29;30-34;35-39;40-44;45-49;50-54;55-59;60-64;65-69;70-74;75-79;80-84;85-89;90+	Yes (care home residents). Age bands: 0-64;65-69;70-74;75-79;80-84;85-89;90+. By date of occurrence ¹⁰⁰ .

⁹⁷ The breakdown by age bands is also available for England and Wales separately (by date of occurrence). Data (available [here](#)) currently cover deaths occurring between 2 March 2020 and 12 June 2020, registered up to 20 June 2020. Age bands: 0-64;65-69; 70-74;75-79;80-84;85-89;90+

⁹⁸ Currently covering deaths occurring between 2 March 2020 and 12 June 2020, registered up to 20 June 2020, available [here](#)

⁹⁹ Footnote 103 applies.

¹⁰⁰ Footnote 104 applies.

Table B: Summary of estimates of deaths of care home residents in the UK during the COVID-19 pandemic

	England	Northern Ireland	Scotland	Wales	UK
Number of beds available (all adult care homes)¹⁰¹	457,428	16,059	38,614	25,555	537,656
Number of COVID-19 related deaths in care homes¹⁰²	14,166	346	1,935	680	17,127
COVID-19 related deaths in care homes as a share of beds¹⁰³	3.10%	2.15%	5.01%	2.66%	3.19%
Number of COVID-19 related deaths of care home residents¹⁰⁴	18,562	423	2,094	826	21,775
COVID-19 attributed related of care home residents as a share of beds¹⁰⁵	4.06%	2.63%	5.42%	3.23%	4.05%
Excess deaths in care homes¹⁰⁶	25,524	406	2,441	1,074	29,445
Excess deaths in care homes as a share of beds¹⁰⁷	5.58%	2.53%	6.32%	4.20%	5.48%

¹⁰¹ See Table 1.

¹⁰² See Table 3.

¹⁰³ Row 2 divided by row 1.

¹⁰⁴ See Table 3.

¹⁰⁵ Row 4 divided by row 1.

¹⁰⁶ Data available [here](#).

¹⁰⁷ Row 6 divided by row 1.