

Excess deaths from all causes, involving and with dementia as the underlying cause: Scotland 2020/2021

**Secondary analysis of National Records of
Scotland deaths data relating to people with
dementia during the coronavirus (COVID-19)
pandemic in different settings**

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Background

With 28% of all deaths involving COVID-19 in 2020 having some category of dementia mentioned on the death certificate, it is necessary to understand the relationship between COVID-19 and dementia excess deaths across all care settings. This paper aims to examine the effect of the COVID-19 pandemic on deaths involving dementia or with dementia as the underlying cause including Alzheimer's disease.

Reference to 'dementia' throughout this document will include people with Alzheimer's disease and other types of dementia.

Deaths 'involving' a particular cause refers to all deaths that had the cause mentioned on the death certificate, as the underlying cause or as a contributory cause.

In response to the reporting by National Records of Scotland (NRS) of an increase in excess deaths attributed to dementia during the pandemic, [Scotland's Data and Intelligence Network](#) set out a number of analytical questions that required evidence to inform clinical and other professional responses to people with dementia who contract COVID-19 in the vaccination and recovery phase.

Part of the required evidence included a clearer indication of whether there had been an increase in the number of deaths of people with dementia that could be attributed to COVID-19 in comparison to the number of dementia-related deaths that occurred before the pandemic.

During April 2021, in response to this evidence request, analysts from the Health and Social Care Analysis Division carried out secondary analysis of weekly statistics published by NRS to identify the number of deaths of people with dementia during the COVID-19 pandemic to date and to compare these figures to the 2015-2019 average, for all settings. Routine NRS statistics included only deaths where dementia was the underlying cause, and it was suspected that there might be additional deaths registered in the same period with other underlying causes of death but with pre-existing dementia. Therefore, an ad hoc request was made to NRS in May 2021 to identify all registered deaths involving dementia i.e. where dementia was mentioned on the death certificate but was not necessarily the underlying cause.

Secondary analysis was conducted to compare the number of deaths of people with dementia during the pandemic with the average number of deaths of people with dementia over the previous five years. In addition, analysis of deaths of all causes during the pandemic compared with deaths over the previous five years is presented below to understand the impact of the pandemic on people with dementia compared to the wider population.

How the data was handled and where it came from

The findings presented in this paper include analysis of deaths of all causes, deaths where *dementia was the underlying cause*, and deaths *involving dementia*. Deaths *involving dementia* refers to deaths where dementia was an underlying or a contributory cause. The underlying cause of death is defined as “the disease or injury which initiated the chain of morbid events leading directly to the death” and a contributory cause of death is a condition which contributed to the occurrence of the death, but was not part of the main sequence leading to the death¹. This paper is secondary analysis of existing data rather than Official or National Statistics.

The **underlying cause of death** is defined as “the disease or injury which initiated the chain of morbid events leading directly to the death”¹.

A **contributory cause of death** is a condition which contributed to the occurrence of the death, but was not part of the main sequence leading to the death.

Weekly registered deaths for 2020-2021 are put into context by comparing to the 2015-2019 average, and the difference between the two is referred to as excess deaths. The World Health Organisation defines excess mortality as the difference in the total number of deaths in a crisis compared to those expected under normal conditions ([The true death toll of COVID-19: estimating global excess mortality \(who.int\)](#)). COVID-19 excess mortality accounts for the total number of deaths directly attributed to the virus as well as the indirect impact, such as the indirect impact of restrictions and disruption to essential health services. NRS provide further information about [choosing a five year average for the measurement of excess deaths](#).

What are ‘excess deaths’?

The total number of deaths registered in a week minus the average number of deaths registered in the same week over the previous five-year period.

NRS publish weekly statistics on [Deaths involving coronavirus \(COVID-19\) in Scotland | National Records of Scotland \(nrscotland.gov.uk\)](#) which includes weekly registered deaths from all causes and by the main underlying causes of death.

Dementia deaths include deaths that are registered with either ICD code F01 (Vascular Dementia), F03 (Unspecified Dementia) or G30 (Alzheimer’s Disease) as the *underlying cause* of death or *mentioned on the death certificate*.

¹ <https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/deaths/deaths-background-information/death-certificates-and-coding-the-causes-of-death/the-medical-certificate-of-the-cause-of-death>

Data sources:

<https://www.nrscotland.gov.uk/files//statistics/covid19/covid-deaths-21-data-week-31.xlsx>

<https://www.nrscotland.gov.uk/files//statistics/covid19/covid-deaths-21-data-week-27.xlsx>

<https://www.nrscotland.gov.uk/files//statistics/covid19/weekly-deaths-involving-dementia-and-alzheimer-disease.xlsx>

<https://www.nrscotland.gov.uk/files//statistics/covid19/annual-deaths-and-excess-deaths-1855-2020.xlsx>

While 2020 figures from NRS are finalised, 2021 figures are provisional and subject to change.

Only one year out of the five in 2015-2019 has a Week 53, therefore the weekly average deaths figure for Week 53 in 2015-2019 has been divided by five before comparing annual 2020 figures to the 2015-2019 average.

Potential limitations of data relating to dementia

Not every individual with dementia has a medical diagnosis. Depending on the method used to estimate prevalence, it is estimated that between 60% ([EuroCoDe](#)) and 85% ([PACSIIm](#)) of people aged 65+ with dementia in Scotland receive a medical diagnosis. PACSIIm is the benchmark used by NHS England, while Alzheimer Scotland prefers EuroCoDe. Further, even if a person has received a medical diagnosis of dementia, this does not mean it will be recorded on the death certificate unless determined as a contributing cause of death. NRS provide [information about the recording of diseases and conditions on death certificates](#). This means that some people who die with dementia as a pre-existing condition will not be included in official statistics that record deaths related to dementia because: either i) dementia was not considered as a contributory factor associated with the person's death, or ii) the person did not receive a formal diagnosis.

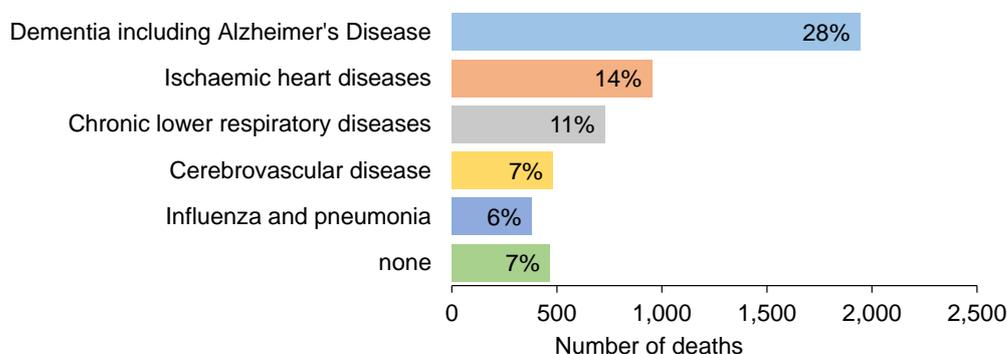
Headline Messages

Dementia is the main pre-existing medical condition in deaths involving COVID-19

From 16 March to 31 December 2020, there were 2,154 deaths registered *involving COVID-19* where *dementia* was also mentioned on the death certificate. Of all deaths *involving COVID-19* and *dementia*, only 3% (66 deaths) were registered with *dementia as the main underlying cause*. In contrast, 95% (2,038 deaths) were registered with *COVID-19 as the main underlying cause* (with the remaining 2% due to some other underlying cause). The number of deaths *involving dementia* that also had COVID-19 mentioned on the death certificate represented 99% of the number of excess deaths *involving dementia*. This supports our assumption that excess deaths registered *involving dementia* in 2020 (2,177) could almost wholly be attributed to COVID-19.

Further, the difference in excess deaths between *dementia as the underlying cause* or *involving dementia* is likely influenced by deaths being registered *involving COVID-19*, as 28% of all deaths *involving COVID-19* in 2020 also had dementia mentioned on the death certificate. Dementia is, to date, the main pre-existing medical condition in all deaths *involving COVID-19*.

Figure 1: Main pre-existing medical conditions in deaths involving COVID-19, Scotland 1 March 2020 to 31 December 2020



The proportion of deaths registered with *dementia* and *COVID-19* in 2020 is higher than the 2015-2019 average proportion of people who died from influenza who also had dementia (15%, see [supplementary table 3](#)). However, it is worth noting that the 2015-2019 annual average of deaths involving influenza registered in Scotland was only 204, in sharp contrast to the 6,702 deaths registered in 2020 with COVID-19 mentioned on the death certificate. Therefore, it is difficult to make comparisons across the two conditions.

When considering the location of death where both *COVID-19* and *dementia* was *mentioned on the death certificate*, 73% of deaths (1,577) occurred in care homes.

Figure 2: Proportion of deaths with dementia and COVID-19 mentioned on the death certificate by setting, Scotland 2020

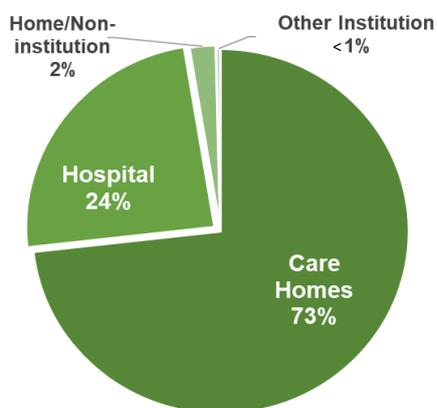


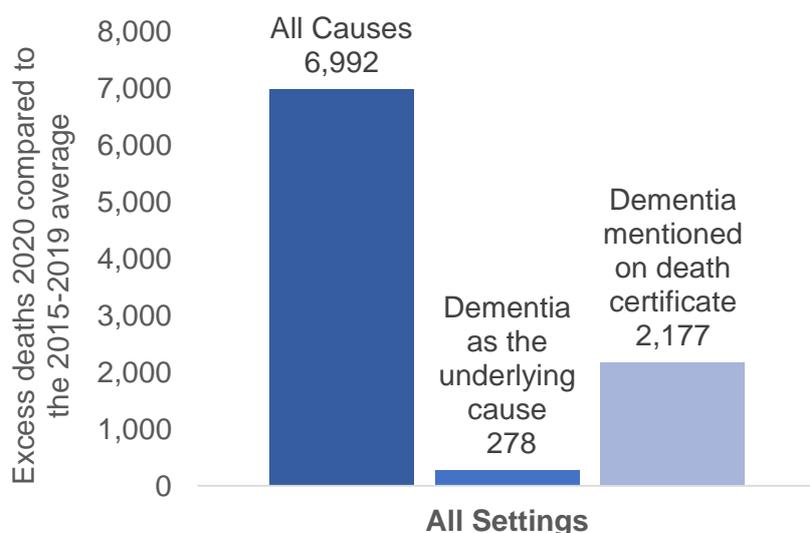
Figure 3: Annual number of deaths with dementia mentioned on the death certificate, Scotland 2015-2020



Deaths involving dementia in 2020 exceeded the 2015-2019 average

In 2020, there were 6,437 deaths registered with *dementia as the underlying cause*. This is 278 (+5%) more deaths than the 2015-2019 average (6,159) with the main spike observed in April 2020 (67% higher²). However, when all registered deaths *involving dementia* are considered, there were 12,492 deaths where *dementia was mentioned on the death certificate*. This is 2,177 (+21%) more deaths than the 2015-2019 average number of deaths with *dementia mentioned on the death certificate* (10,315). Deaths from all causes exceeded the 2015-2019 average by 6,992 deaths (+12%).

Figure 4: Excess deaths in all settings, Scotland 2020 compared to the 2015-2019 average



² https://www.nrscotland.gov.uk/files/statistics/rgar/2020/scotlands-population-2020.html#april_2020_saw_a_spike_in_dementia_and_alzheimer's_deaths

Notes on annual dementia death statistics published by NRS

The 2021 [NRS report Alzheimer's disease and other dementias](#) published on 17 September shows that deaths registered with *dementia as the underlying cause* were 3% higher³ in 2020 compared to the 2015-2019 average and 10% higher in 2019 compared to the 2014-2018 average ([see NRS table](#)). This shows that excess deaths from dementia including Alzheimer's disease were lower in 2020 than in 2019 and sit within what might be expected as normal year-on-year variation. However, NRS note that these statistics are affected by a change in cause of death coding software at the beginning of 2017. For further comparison, annual excess deaths (all causes) 2001-2019 ([see supplementary table 4](#)) ranged from -4% to +6%.

Proportionally, excess deaths in care homes in 2020 exceeded excess deaths in all settings

A large proportion of excess deaths *involving dementia* in 2020 were registered to have occurred in care homes, a setting which has a high proportion of individuals diagnosed with dementia (estimated at 64% of residents in care homes for older people, [see the Public Health Scotland Care home census](#)). Further, 41% of deaths with *COVID-19 as the underlying cause* in 2020 were registered to have occurred in care homes. In 2020, there were 15,886 deaths (from all causes) registered in care homes. This is an excess of 2,352 deaths (+17%) compared to the 2015-2019 average (13,534). Proportionally, this is higher than excess deaths from all causes in all settings in 2020, which was +12% (64,823 registered deaths in 2020 compared to the 2015-2019 average of 57,831 deaths).

Figure 5: Deaths with COVID-19 as the underlying cause by location, Scotland 2020

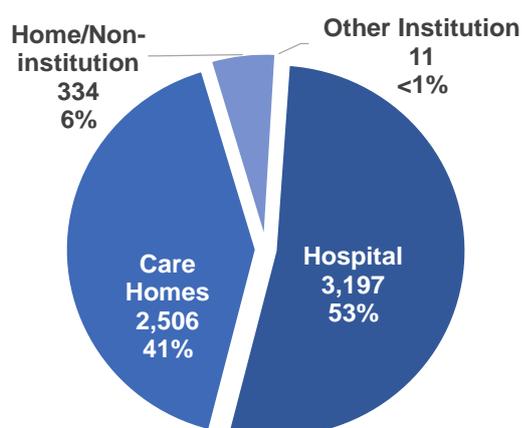
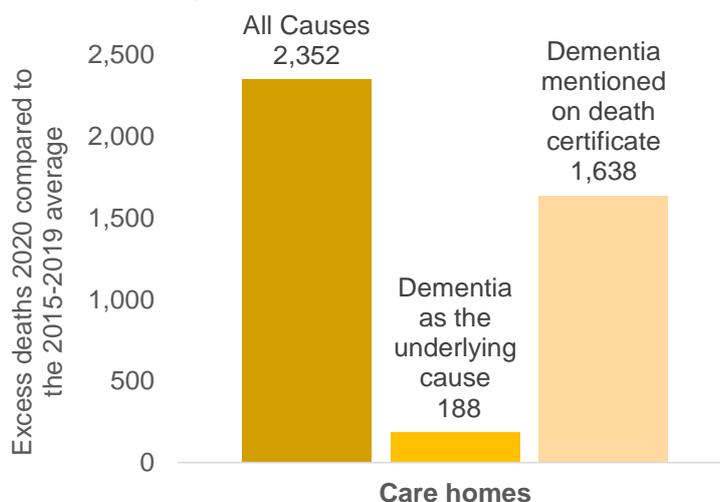


Figure 6: Excess deaths in care homes, Scotland 2020 compared to the 2015-2019 average



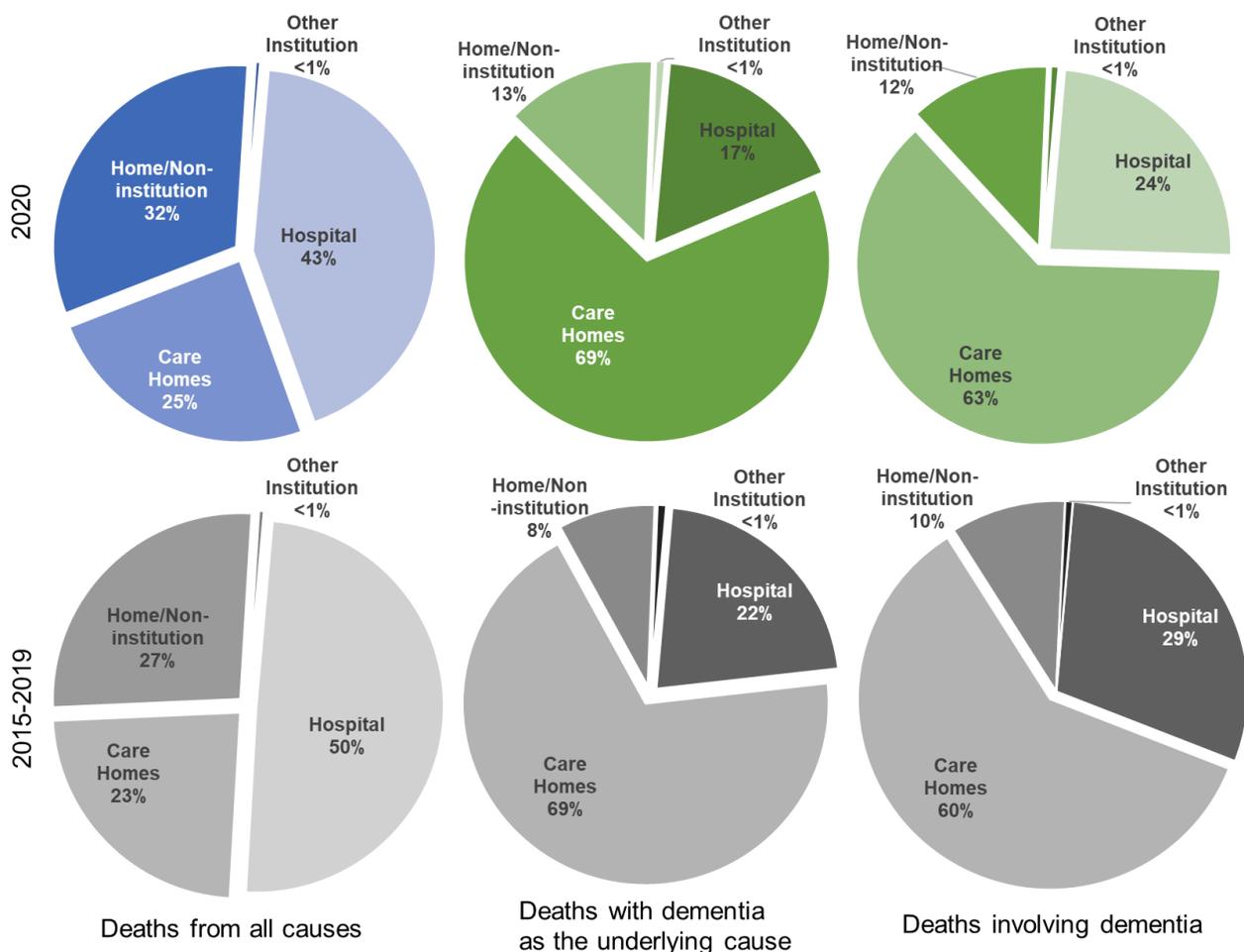
³ The percentage of excess deaths differs slightly from analysis in the current report (5% above average) as analysis in the NRS report is based on annual rather than weekly figures (corrected for number of days in weeks 1 and 53)

Figure 7 shows the proportion of deaths registered in 2020 in different settings. 25% of deaths from all causes (15,886) were registered in care homes in 2020, which is similar to the proportion of 2015-2019 average deaths from all causes registered in care homes (23%, 13,534).

Further, 69% of all deaths registered in 2020 with *dementia as the underlying cause* occurred in care homes (4,424). This is the same proportion as that of all deaths registered with *dementia as the underlying cause* on average over 2015-2019 that occurred in care homes (69%, 4,236). 63% (7,837) of all deaths *involving dementia* registered in 2020 were in care homes, compared to a 2015-2019 average of deaths *involving dementia* in care homes of 60% (6,199).

This indicates that while excess deaths from all causes were higher in care homes than in all settings, the proportion of deaths registered in care homes in 2020 was proportionally only slightly increased when compared with previous years.

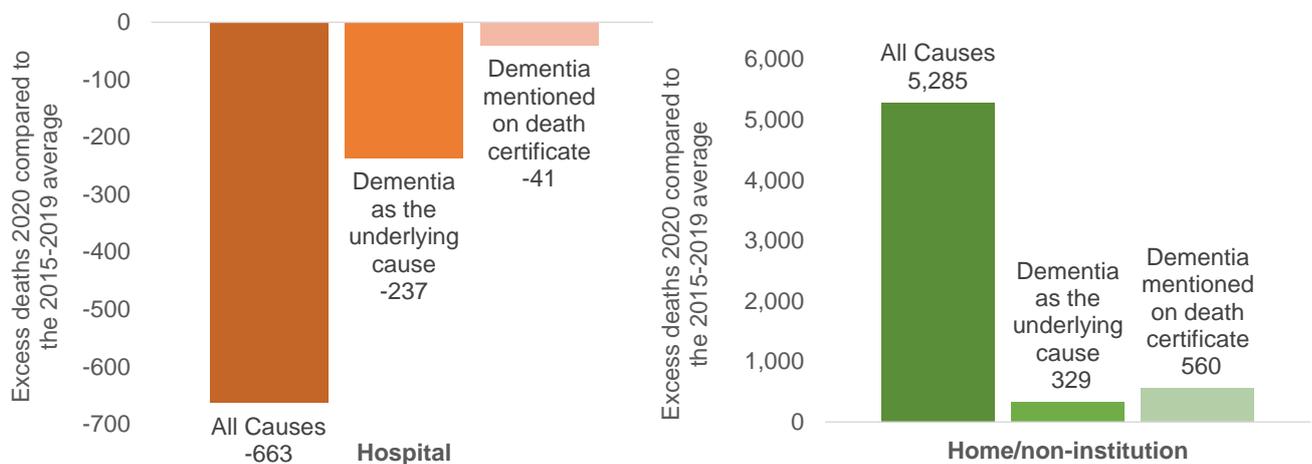
Figure 7: Proportion of deaths in 2020 and average of 2015-2019 by setting of death, all causes, dementia as the underlying cause and deaths involving dementia



Deaths where dementia was the underlying cause were lower in hospital and higher at home/non-institutional setting in 2020

When looking at settings for deaths where *dementia was the underlying cause* in 2020, there were 329 excess deaths at home/non-institutional setting (+63% above the 2015-2019 average). Please note that the high percentage change is primarily due to a low number of weekly registrations and a low five-year average in this setting. At the same time, there were 237 fewer deaths in hospital (-18%) compared to the five-year average, suggesting that the excess deaths with *dementia as the underlying cause* at home/non-institutional setting may be due in part to a shift in location of deaths. For care homes, there were 188 excess deaths (+4%) with *dementia as the underlying cause* (see Fig. 6).

Figure 8: Excess deaths in hospital and at home/non-institutional setting, Scotland 2020 compared to the 2015-2019 average



Deaths involving dementia were higher in care homes and at home/non-institutional setting, and slightly lower in hospital in 2020

For deaths *involving dementia* (mentioned on the death certificate) in 2020, there were 560 excess deaths at home/non-institutional setting (+56%), 1,638 excess deaths in care homes (+26%), and 41 fewer deaths compared to the 2015-2019 average in hospital (-1%).

The highest weekly number of deaths *involving dementia* in care homes (406) was recorded mid-way through the first wave of the COVID-19 pandemic in Week 17 2020 (week beginning 20 April 2020). This likely reflects COVID-19 deaths amongst people with dementia at this point in the pandemic since 51% of all deaths *involving COVID-19* during this week in care homes also had dementia mentioned on the death certificate (207). COVID-19 involvement in deaths at this point may be underreported, since testing was less widespread outside hospital settings and there was less awareness of the full range of COVID-19 symptoms at the beginning of the first wave of the pandemic.

Average weekly excess deaths reduced over the course of the pandemic with the greatest reduction observed in care homes

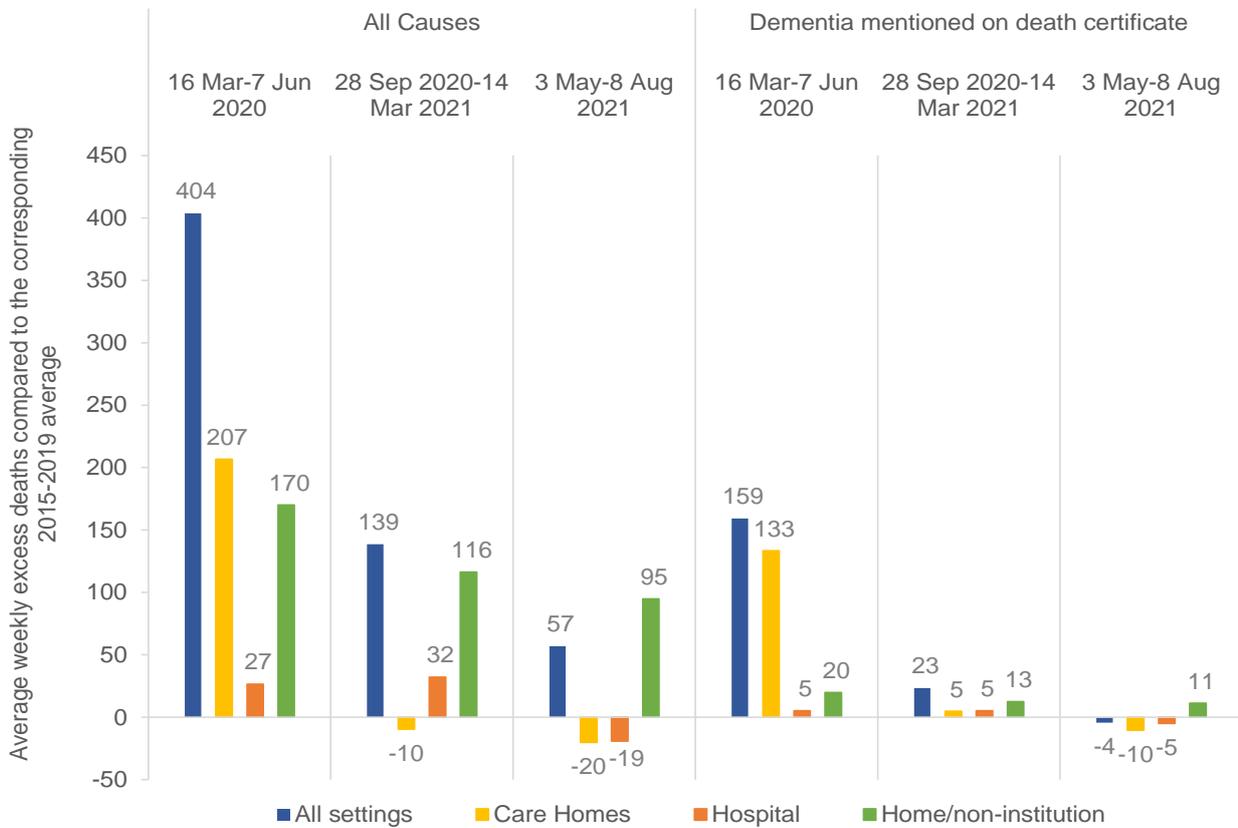
There was a reduction in excess deaths (all causes and dementia-related) over the course of the pandemic. Three periods were compared, 16 March to 7 June 2020 (equivalent to the first wave), 28 September 2020 to 14 March 2021 (equivalent to the second wave) and 3 May to 8 August 2021 (when more than 90% of all older adults in care homes and care home staff had received two doses of a COVID-19 vaccine). Average weekly excess deaths were compared to account for the different length of time of each period.

The reduction in weekly average excess deaths was largely driven by a reduction in excess deaths observed in care homes. This may be a result of improved measures to reduce infection in care homes, and the vaccine rollout which prioritised care homes and older people, and/or due to higher 2015-2019 weekly average deaths during autumn/winter compared to spring/summer. However, further analysis would be required to establish the relative contribution, if any, of each of these factors.

The reduction in weekly average deaths may also be related to the peak in excess deaths caused by dementia at the start of the pandemic. Some of these deaths may have involved COVID-19 even if not registered on the death certificate, as indicated above, since testing was less widespread outside hospital settings and there was less awareness of all COVID-19 symptoms.

The gradual reduction in excess deaths over these three periods points to a positive effect of protective measures to reduce infections and/or the vaccine programme. However, related to the likely hastening of some deaths *involving dementia*, and the long period of restrictions, it is worth noting that death registrations during summer 2021 were much lower than the previous two periods. This lower number of registrations will have contributed to the overall trend of a reduction in excess deaths *involving dementia*.

Figure 9: Average weekly excess deaths, all causes and involving dementia, by setting, Scotland 16 March to 7 June 2020, 28 September 2020 to 14 March 2021 and 3 May to 8 August 2021 compared to the corresponding 2015-2019 average



Conclusions

Dementia is the most common pre-existing condition in COVID-19-related deaths

There is a clear link between COVID-19 and pre-existing health conditions, with over 90% of COVID-19-related deaths registered with at least one pre-existing condition⁴. In 2020, dementia was the most common pre-existing condition: it was present in 1 in 4 COVID-19-related deaths.

Deaths involving dementia were 21% higher in 2020 compared to the five-year average

In 2020, there were 5% more deaths *caused by dementia* compared to the five-year average, with the main spike observed in April 2020 (67% higher⁴). While this was proportionally less than excess deaths from all causes (12% higher than the five-year average), excess deaths *involving dementia* in 2020 were 21% higher than the five-year average.

To better understand the impact of the pandemic on deaths of people diagnosed with dementia, deaths *involving dementia* were analysed regardless of the cause that led to these deaths. Deaths *involving dementia* include deaths registered with dementia as either a contributory or underlying cause of death. The analysis suggests that excess deaths *involving dementia* in 2020 could almost wholly be attributed to COVID-19. The number of deaths *involving dementia* that also had COVID-19 mentioned on the death certificate represented 99% of the number of excess deaths *involving dementia*.

There were fewer deaths in hospital and more deaths in care homes and at home/non-institutional setting in 2020 compared to the five-year average

When looking closer at the setting where deaths *involving dementia* were registered in 2020:

- **Care Homes:** 1,638 excess deaths *involving dementia* (26% higher than the five-year average). Deaths *involving dementia* and *COVID-19* represented 96% of this number. 59% of deaths *involving COVID-19* in care homes also involved dementia.
- **Hospital:** 521 deaths *involving dementia and COVID-19*, however, deaths *involving dementia* were 1% lower than the five-year average (41 fewer deaths). 14% of deaths *involving COVID-19* in hospital also *involved dementia*.
- **Home/Non-institutional setting:** 560 excess deaths *involving dementia* (56% higher than the five-year average). The number of deaths *involving dementia* and *COVID-19* represented only 9% of this number (48 deaths).

⁴ <https://www.nrscotland.gov.uk/files/statistics/rgar/2020/scotlands-population-2020.html>

It is important to note that the overall number of deaths registered at home/non-institutional setting is lower than in care homes and in hospital, which is reflected as a higher percentage change. These data suggest a shift in the location of deaths *involving dementia* in 2020 compared to the five-year average, with more people with dementia dying at home/non-institutional setting compared to in hospital. However, more deaths *involving dementia* and *COVID-19* were registered in hospital than at home/non-institutional setting.

Excess deaths involving dementia reduced over the course of the pandemic

After the initial peak of excess deaths in April 2020 during the first wave of the pandemic, deaths *caused by dementia* were consistently lower than the five-year average, in particular over the winter period. Deaths *involving dementia* in the second wave initially exceeded the five-year average, but were considerably lower compared to the first wave. Between March and May 2021 deaths *involving dementia* remained below the five-year average. By setting, the largest reduction in excess deaths over the course of the pandemic was observed in care homes, albeit this still remained the setting where most deaths *involving dementia* occurred.

The reduction in excess deaths may be linked to vaccination and improved measures for reducing infections in care homes

The reduction in excess deaths *involving dementia* over the course of the pandemic may relate to improved measures to reduce infection in care homes and the prioritisation of care home residents and staff in the vaccination programme, in addition to higher average reporting of deaths in winter. This reduction is also likely to be related to the peak in excess deaths *caused by dementia* at the start of the pandemic. Some of these deaths may have involved COVID-19 even if not registered on the death certificate, since testing was less widespread outside hospital settings and there was less awareness of all COVID-19 symptoms at the beginning of the first wave. With the rollout of the vaccination programme in care homes in early 2021, it is possible that the effects of vaccination are observable already during the second wave. Average weekly excess deaths in care homes and *involving dementia* were greatly reduced in the second wave, to below average levels in summer 2021.

While more work is required to understand the link between the COVID-19 pandemic and deaths from other causes, it is likely that some people who died from COVID-19 in 2020 would have died from other causes such as dementia, heart disease or respiratory disease. However, their deaths may have been hastened by COVID-19 infection. Further, some excess deaths registered as being *caused by dementia* at the start of the pandemic may have involved COVID-19 if the person was not tested for infection before their death. In conclusion, COVID-19 disproportionately affected people with dementia (and people with other pre-existing conditions) and led to excess deaths *involving dementia*, particularly early in the pandemic in care homes.



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