Excess deaths from all causes, involving and with dementia as the underlying cause: Scotland 2020-2022

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Scottish Government
Riaghaltas na h-Alba

Contents

Background

This report examines the effect of the COVID-19 pandemic on *deaths involving dementia* including Alzheimer's disease from March 2020 to March 2022. It follows previous Scottish Government analysis that examined deaths involving dementia including Alzheimer's disease in Scotland from March 2020 to August 2021.

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.

National Record of Scotland (NRS) statistics showed a marked increase in *deaths with dementia as the underlying cause* in the early stages of the COVID-19 pandemic, and established that dementia was the most common pre-existing medical condition amongst those whose deaths involved COVID-19. In response, the Scottish Government committed to further work to understand excess deaths as part of the Dementia COVID-19: Action Plan Coronavirus (COVID-19) (2020).

Stakeholder engagement led to the Scottish Government's Dementia COVID-19: Action Plan and helped to inform its commitments. The Plan identified a need to understand the relationship between both the COVID-19 virus and the impact of restrictions on the progress of the dementia illness, health outcomes and excess deaths rates across all care settings. The Scottish Government committed to commissioning and publishing analysis in this area. 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.

In response to this evidence request, analysts from the Health and Social Care Analysis Division in the Scottish Government carried out secondary analysis of weekly statistics published by NRS. This analysis involved identifying the number of *deaths involving dementia* during the COVID-19 pandemic and comparing these figures to the five year average, for all settings. Routine NRS statistics only included deaths where dementia was the underlying cause. These statistics would omit the deaths of individuals who had a dementia diagnosis and had been impacted by COVID-19 infection, as COVID-19 would likely be noted as the underlying cause (with dementia as a contributory cause). Therefore, ad hoc requests were made to NRS to identify all registered *deaths involving dementia* i.e. where dementia was mentioned on the death certificate as either the underlying or a contributory cause.

Secondary analysis was conducted to compare the number of *deaths involving dementia* during the pandemic with the average number of *deaths involving dementia* over the previous five years. In addition, analysis of *deaths from all causes* during the pandemic compared with deaths over the previous five years was used to provide broader context of the impact of the pandemic on the general population.

Analysis of excess deaths involving other medical conditions were out of scope for this report. This should not be interpreted as other causes of death during the pandemic being less relevant or important than deaths involving dementia.

It is important to note that these are mortality statistics and as such are unable to provide insight on the lived experience of any individual with dementia who died during the time period analysed. While other evidence to understand the experiences and broader health outcomes of people with dementia is important and necessary to understand the full impact of the pandemic, these are out of scope for this report on excess deaths.

COVID-19 Public Inquiry

A Public Inquiry has been established to examine the handling of the COVID-19 pandemic in Scotland. The Inquiry works independently of government. It will provide scrutiny of and learn lessons from the handling of the COVID-19 pandemic in Scotland, to ensure that Scotland is as prepared as possible for future pandemics.

The Scottish Government remains committed to providing high quality evidence and data to understand the impact of the pandemic on excess mortality and to support resilience and recovery. We work in close partnership with Public Health Scotland and the National Records of Scotland to learn lessons and we will continue to closely monitor excess deaths.

Data handling, definitions and sources

NRS publish weekly statistics on Deaths involving coronavirus (COVID-19) in Scotland which include weekly registered deaths from all causes and by the main underlying causes of death. Death certificates of those who died with COVID-19 were examined to look at their pre-existing conditions. Pre-existing conditions are defined by NRS as a health condition mentioned on the death certificate which either came before COVID-19 or was an independent contributory factor in the death.

This report presents secondary analysis of existing data from NRS. The findings include analysis of deaths from 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.

NRS defines the underlying cause of death 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 death (please see the NRS website for further background about death certificates and coding the causes of death).

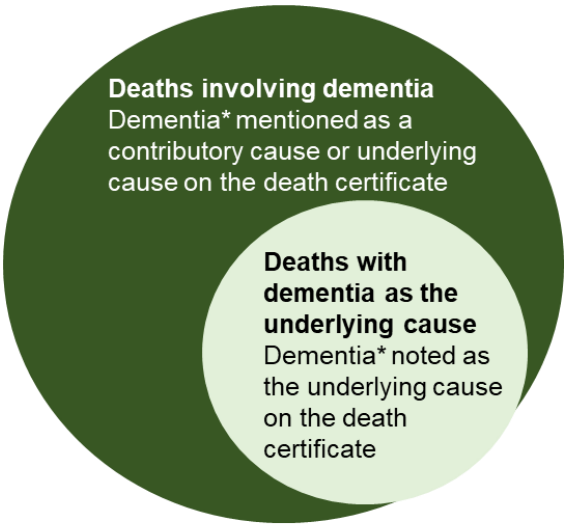
The **underlying cause of death** is defined as the disease or injury which initiated the chain of morbid events leading directly to the death.

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.

A condition must have contributed to the death for it to be mentioned on the death certificate. Since NRS data list only those conditions recorded as a contributory or underlying cause of death, this analysis cannot separate deaths where dementia was the only pre-existing health condition at the time of death from deaths where dementia was one condition amongst other comorbidities at the time 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 as a contributory cause.*

Deaths with *dementia as the underlying cause* are therefore a subset of deaths *involving dementia (*which include deaths mentioned as either an underlying or contributory cause*).*



*ICD codes F01, F03 and G30

Weekly registered deaths for 2020 were put into context by comparing to the 2015-2019 average, and the difference between the two is referred to as excess deaths.

In 2021, NRS continued to use the 2015-2019 average to measure excess deaths. It was not appropriate to compare against the 2016-2020 average in 2021, as that would have been affected by the pandemic with higher deaths in Spring 2020. However, by using the 2015-2019 average in 2021, there is a risk that we have overestimated excess deaths, by not fully accounting for the ageing population.

For 2022, the excess deaths calculation would usually incorporate the mortality data for the most recent 5 year period (2017-2021). However, given the unusual nature of the 2020 data and the decision previously taken for 2021, NRS decided to use the average of 2016, 2017, 2018, 2019 and 2021, and therefore continue to exclude 2020 from the five-year average.

Further detail on the excess deaths methodology is provided in the Limitations section, and NRS have published a paper on choosing a five year average for the measurement of 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.

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.

In a period of excess deaths, which can be a result of an infection such as COVID-19 or an external factor such as a heat wave, mortality displacement can occur. Mortality displacement refers to vulnerable individuals who are near the end of their life dying earlier than expected. If a large number of deaths are hastened, a period of mortality deficit might be expected.

What is 'mortality displacement'?

Vulnerable individuals who are near the end of their life dying earlier than expected. This may be due to an infection or external factors. If a large number of deaths are hastened, a period of mortality deficit might be expected.

This analysis considers total excess deaths across all settings, as well as excess deaths in three separate settings: in care homes, in hospitals and at home or non-institutional settings, reflecting the categories of settings reported in NRS statistics. With nearly two thirds of adult care home residents having some degree of dementia (see the Public Health Scotland Care Home Census 2022), care homes are a setting that demands particular attention in relation to the analysis of excess deaths involving dementia and with dementia as the underlying cause.

While 2020 and 2021 figures from NRS are finalised, 2022 figures are provisional and subject to change. To ensure comparability, we have focussed on comparisons between 2020 and 2021, but we have considered data up to March 2022 where possible. The underlying data are available in the supplementary tables.

Main points

- Between 1 March 2020 and 31 March 2022, dementia was the most common pre-existing medical condition mentioned on the death certificate in *deaths involving COVID-19*.

Deaths registered involving dementia

- In 2020, there were 12,492 *deaths involving dementia* (as the underlying or a contributory cause of death), representing 2,177 excess deaths.
- In 2021, there were 10,626 *deaths involving dementia*, representing 311 excess deaths, therefore showing a reduction in excess deaths across the two years.
- The main spike in *excess deaths involving dementia* was observed during the first wave of the pandemic in April 2020.

Deaths registered involving dementia and COVID-19

- In 2020, there were 2,154 *deaths involving dementia and COVID-19*, which decreased to 1,000 deaths in 2021.
- In 2020 the number of *deaths involving dementia and COVID-19* almost equalled the number of *excess deaths involving dementia,* but in 2021 there were over three times more *deaths involving dementia and COVID-19* than there were *excess deaths involving dementia*. This may be a result of mortality displacement, offset by continued *deaths involving COVID-19*.
- Of *deaths involving dementia and COVID-19,* the proportion *with dementia as the underlying cause* increased from 3% in 2020 to 12% in 2021, while the proportion *with COVID-19 as the underlying cause* decreased from 95% to 82%.

Deaths registered by setting of occurrence

- In 2020, 73% of *deaths involving dementia and COVID*-19 occurred in care homes, compared to 53% in 2021.
- The number of *deaths with COVID-19 as the underlying cause* decreased between 2020 and 2021, but the proportion occurring in hospital increased.
- In 2020, there were a large number of *excess deaths involving dementia* in care homes and at home or non-institutional settings. However, in 2021 there were fewer *excess deaths involving dementia* overall, with only home or non-institutional settings experiencing an excess.
- In 2020, there were a large number of *excess deaths with dementia as the underlying cause* at home or non-institutional settings. In 2021, there was an increase in *excess deaths with dementia as the underlying cause* at home or in non-institutional settings, however *deaths with dementia as the underlying cause* reduced to below average levels as a whole.

Executive summary

COVID-19 disproportionally affected individuals with pre-existing medical conditions, and dementia is the most common pre-existing condition in *deaths involving COVID-19*. Secondary analysis of National Records of Scotland mortality data in this report demonstrates that in 2020 *excess deaths involving dementia* (where dementia was either a contributory or an underlying cause of death) was proportionally greater than *excess deaths from all causes*. This highlights the devastating impact of COVID-19 on individuals with dementia, particularly early in the pandemic in care homes.

Statistics suggest that *excess deaths involving dementia* in 2020 could be attributed almost wholly to COVID-19 infection. However, it is important to note that this analysis does not establish whether these deaths were avoidable.

The data for 2021 show that *excess deaths from all causes* increased in line with *deaths involving COVID-19*. In contrast, *deaths with dementia as the underlying cause* dropped to below average levels in 2021, demonstrating mortality displacement. While *deaths involving dementia* reduced in number, they remained above average in 2021. This finding is likely to be a result of continuing *deaths involving COVID-19*.

However, *deaths involving dementia* and *from all causes* reduced to below average levels in care homes. In addition to mortality displacement, the reduction in *excess deaths involving dementia* in care homes that has taken place 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.

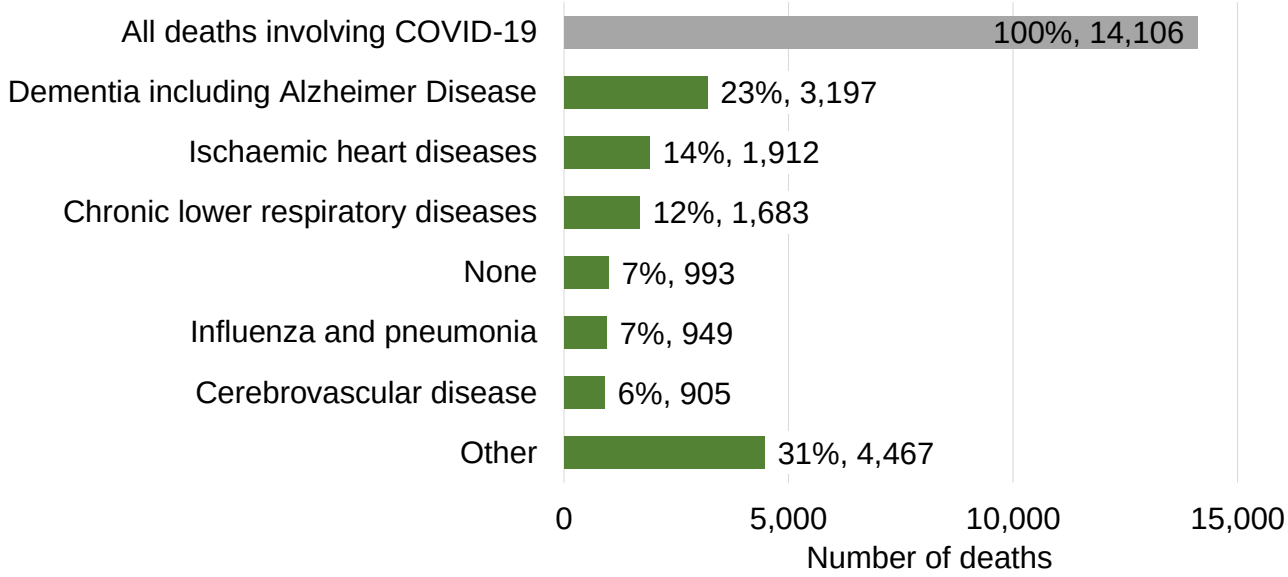
Further, it is important to note that the high number of deaths that occurred in early stages of the pandemic is likely to have impacted the size of the care home population. This has happened in the wider context of a long-term reduction in the number of residents in care homes. Care homes were subsequently under-occupied and hence the total number of deaths would be expected to be lower. This will impact the statistics for later periods when we compare excess deaths between 2020 and 2021.

While fewer *deaths involving dementia* were registered in hospital compared to care homes for 2020 and 2021, an increased proportion of all *deaths involving dementia* in Scotland were registered in hospital in 2021 compared to 2020. This proportional increase may reflect changed approaches to treatment for COVID-19 later in the pandemic: it is possible that care home residents who were severely ill were more likely to be transferred to hospital for treatment and end of life care.

Similarly to *deaths from all causes*, *deaths involving dementia* at home or non-institutional settings continued to remain at above average levels in 2021.

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

Figure 1: Main pre-existing medical conditions in deaths involving COVID-19, Scotland 1 March 2020 to 31 March 2022.



Of all *deaths involving COVID-19* between 1 March 2020 and 31 March 2022, 93% had some pre-existing medical condition. Pre-existing conditions are defined as a health condition mentioned on the death certificate which either came before COVID-19 or was an independent contributory factor in the death.

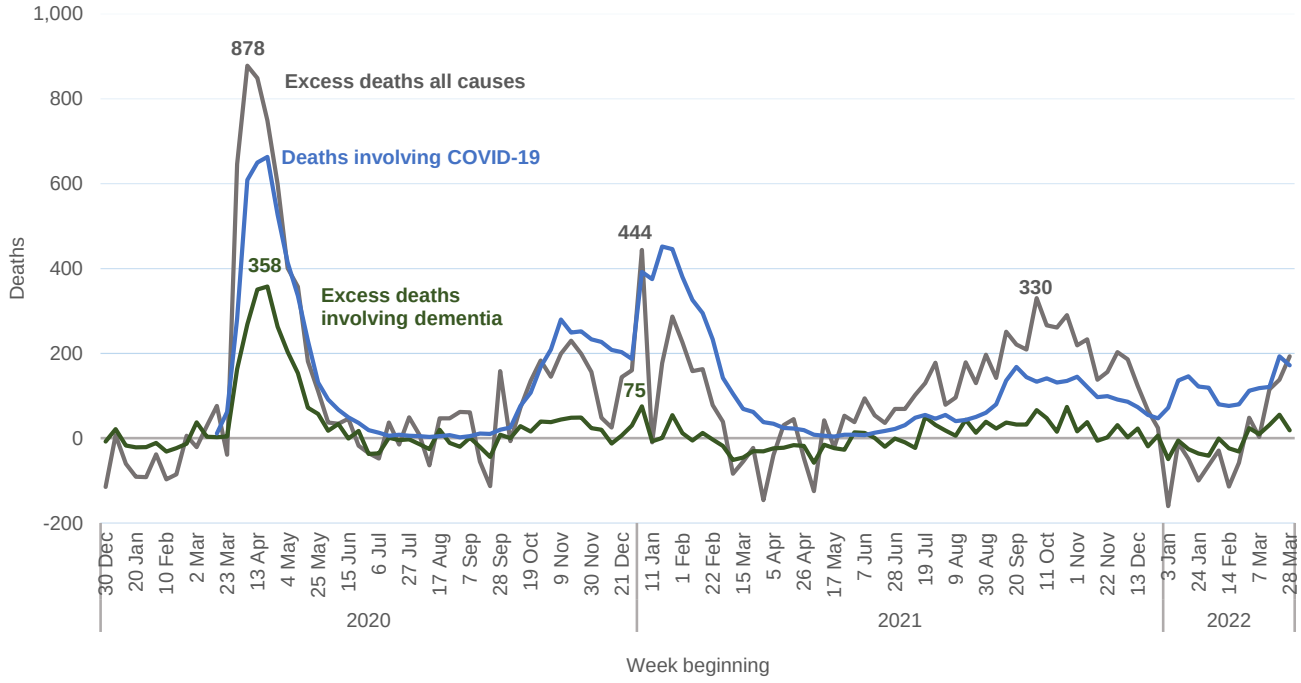
Dementia is the most common pre-existing medical condition in *deaths involving COVID-19*. 23% (3,197) of all *deaths involving COVID-19* also have dementia mentioned on the death certificate. The second most common pre-existing medical condition in *deaths involving COVID-19* is ischaemic heart diseases (14%, 1,912) and the third most common is chronic lower respiratory diseases (12%, 1,683).

The oldest age groups have been most affected by COVID-19, with NRS reporting that more than three quarters of *deaths involving COVID-19* were amongst those aged 75 and over[1]. With age being the greatest risk factor for dementia, this is a condition that is more prevalent among older age groups [2]. Since both dementia and COVID-19 disproportionately affect older people, the involvement of dementia in some COVID-19 deaths would be expected.

[1] https://www.nrscotland.gov.uk/files/statistics/rgar/2019/Pages/cov-sec.html
[2] http://www.healthscotland.scot/health-topics/dementia

Weekly excess deaths were highest at the start of the pandemic

Figure 2: Weekly number of excess deaths from all causes and involving dementia in all settings compared to the five-year average, Scotland 2020 to 2022

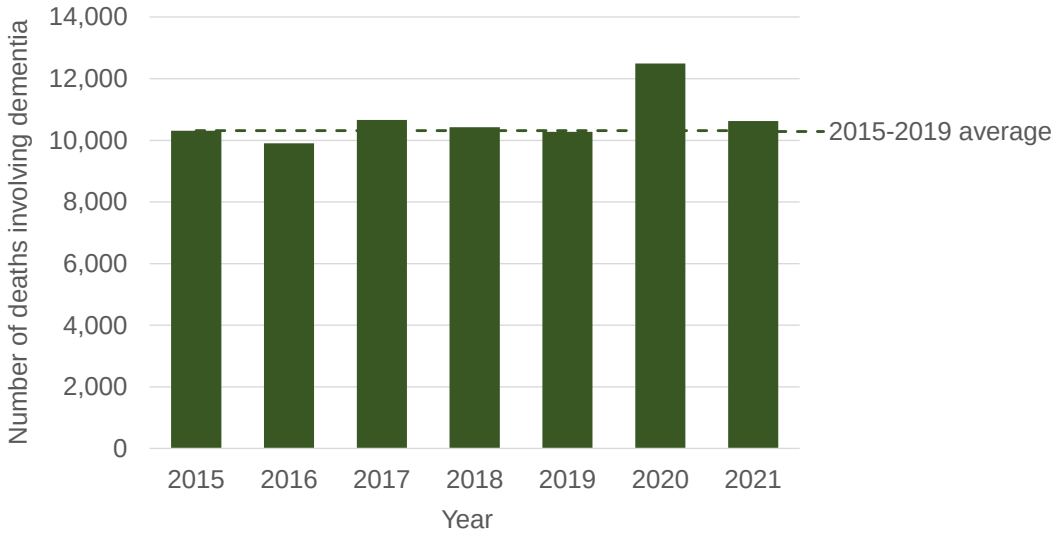


Excess deaths did not occur uniformly throughout the pandemic but were registered over three main periods (which coincided with high numbers of COVID-19 deaths); April 2020, October 2020 to March 2021, and June to December 2021. Weekly *excess deaths from all causes* peaked at the start of the pandemic.

Note weekly death registrations are particularly variable around public holidays due to the closure of Register Offices, as longer delays between occurrences and registration are expected.

Deaths involving dementia moved closer to the average in 2021

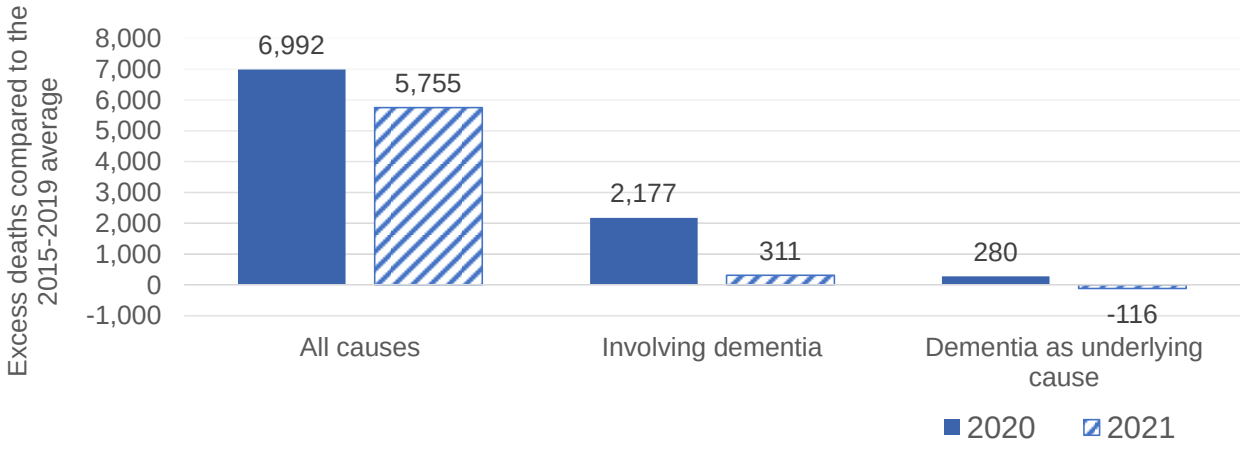
Figure 3: Annual number of deaths involving dementia in all settings (as the underlying or a contributory cause), Scotland 2015-2021



In 2020, there were 12,492 *deaths registered involving dementia* (as the underlying or a contributory cause of death). This is 2,177 more deaths than the 2015-2019 average. In 2021, while excess deaths occurred, *deaths registered involving dementia* were much closer to the average at 10,626 deaths (311 excess deaths).

Total annual deaths with dementia as the underlying cause reduced to below average in 2021, reflecting mortality displacement

Figure 4: Annual excess deaths compared to the 2015-2019 average in all settings, Scotland, 2020 and 2021



Deaths involving dementia and deaths with dementia as the underlying cause, compared with deaths from all causes, total across all settings

In 2020, *deaths from all causes* exceeded the 2015-2019 average by 6,992 deaths (+12%). There were 2,177 *excess deaths involving dementia* (+21%), including 280 *excess deaths with dementia as the underlying cause* (+5%).

In 2021, *deaths from all causes* exceeded the 2015-2019 average by 5,755 deaths (+10%). *Deaths registered involving dementia* were closer to average (311 excess deaths; +3%), and *deaths with dementia as the underlying cause* were below average by 116 deaths (-2%).

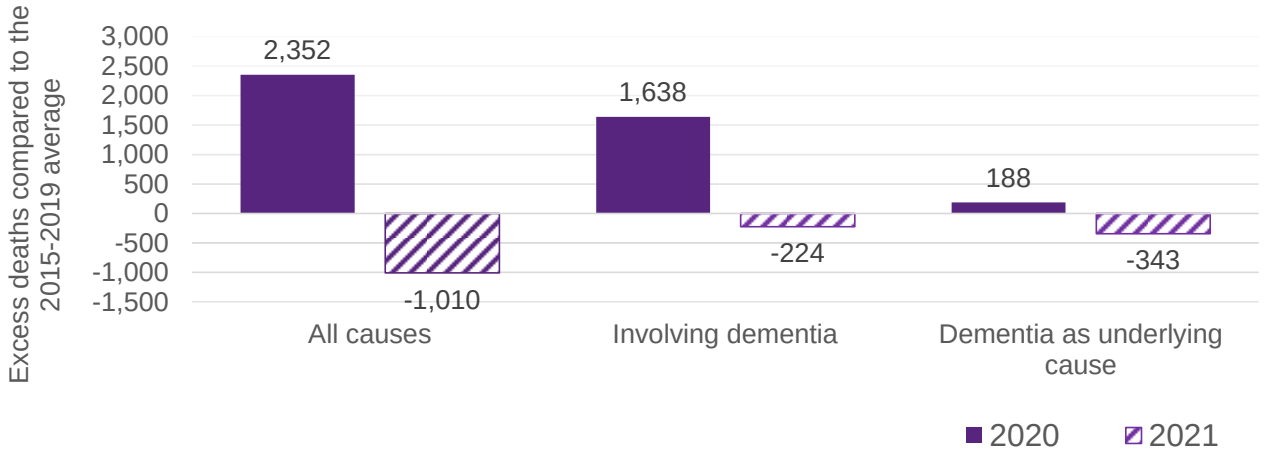
Deaths involving dementia and COVID-19, total across all settings

In 2020, the number of *deaths involving dementia and COVID-19* was similar to the number of *excess deaths involving dementia*. However in 2021, there were over three times more *deaths involving dementia and COVID-19* than there were *excess deaths involving dementia*. This may be a result of mortality displacement, offset by continued *deaths involving COVID-19* or *with COVID-19 as the underlying cause*. Mortality displacement occurs when vulnerable individuals who are near the end of their life die earlier than expected. This can be due to an infection or external factors such as heat waves. If a large number of deaths are hastened, a period of mortality deficit might be expected.

Due to data limitations, *excess deaths involving dementia* are not disaggregated into excess deaths without COVID-19 involvement, therefore no conclusions can be drawn on the impact of indirect harms from the pandemic, such as any changes to care packages or restrictions on visiting to care homes.

In care homes, deaths from all causes, involving dementia, and with dementia as the underlying cause reduced to below average levels in 2021

Figure 5: Annual excess deaths compared to the 2015-2019 average in care homes, Scotland, 2020 and 2021



Deaths involving dementia and deaths with dementia as the underlying cause, compared with deaths from all causes, in care homes

In 2020, three quarters of *excess deaths involving dementia* occurred in care homes, a setting which has a high proportion of individuals diagnosed with dementia (estimated at 62% of residents in care homes for older people, see the Public Health Scotland Care Home Census 2022).

In 2020, there were 2,352 (+17%) *excess deaths from all causes* in care homes compared to the care home 2015-2019 average. *Deaths involving dementia* and *deaths with dementia as the underlying cause* also exceeded the average in 2020 with 1,638 (+26%) and 188 (+4%) excess deaths, respectively.

In 2021, there were 1,010 fewer (-7%) *deaths from all causes* in care homes compared to the care home 2015-2019 average. *Deaths involving dementia* and *deaths with dementia as the underlying cause* were below average in 2021 with -224 (-4%) and -343 (-8%) fewer deaths, respectively.

Deaths involving dementia and COVID-19, in care homes

In care homes, in 2020, the number of *deaths involving dementia and COVID-19* (1,577) was similar to the number of *excess deaths involving dementia* in care homes (1,638).

In 2021, there were fewer *deaths involving dementia and COVID-19* (530) compared to 2020, and *deaths involving dementia* (-224) were below average.

Changing care home occupancy

It is important to note that these figures are likely impacted by the high number of deaths that occurred in Spring 2020. This reduced the size of the care home resident population and care homes were subsequently under-occupied, and we would expect a lower number of deaths with reduced occupancy in 2021. Between 2011 and 2021, the estimated number of residents in care homes for older people decreased by 9%, from 33,645 to 30,502, and by 6% between 2019 and 2021, from 32,445 to 30,502 (see the Public Health Scotland Care Home Census 2021).

This decrease in care home occupancy has occurred in the context of a long-term reduction in the number of care home residents over the last decade despite a growing older population in Scotland, which may relate to a policy emphasis on supporting people to live independently in the community.

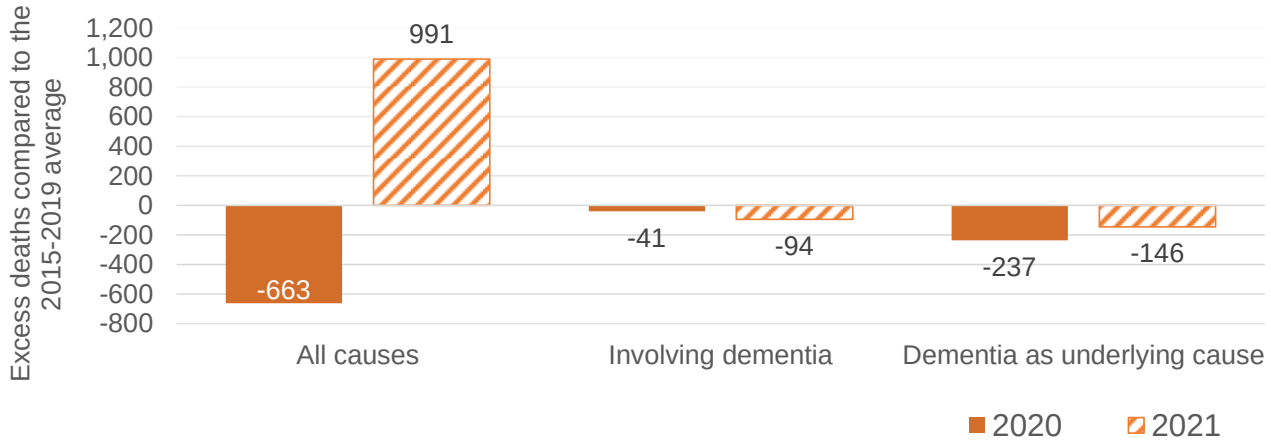
Alongside this observed trend, public awareness of the high level of excess deaths in care homes in the first wave of the pandemic may have affected decisions about whether to stay in a care home.

It is possible that both these factors influenced the level of care home occupancy in 2021.

Care home occupancy remained relatively stable between 2021 and 2022 with a small increase in the number of residents: there were 30,552 residents in care homes for older people on 31 March 2022 (see the Public Health Scotland Care Home Census 2022).

In hospitals, deaths involving dementia and deaths with dementia as the underlying cause were below average in 2020 and 2021, in contrast to deaths from all causes which moved from below average in 2020 to above average in 2021

Figure 6: Annual excess deaths compared to the 2015-2019 average in hospitals, Scotland, 2020 and 2021



Deaths involving dementia and deaths with dementia as the underlying cause, in hospital, compared with deaths from all causes

In hospital, in 2020, there were 663 fewer *deaths from all causes* compared to the 2015-2019 average (-2%). *Deaths involving dementia* and *deaths with dementia as the underlying cause* were also below average with -41 (-1%) and -237 (-18%) fewer deaths, respectively.

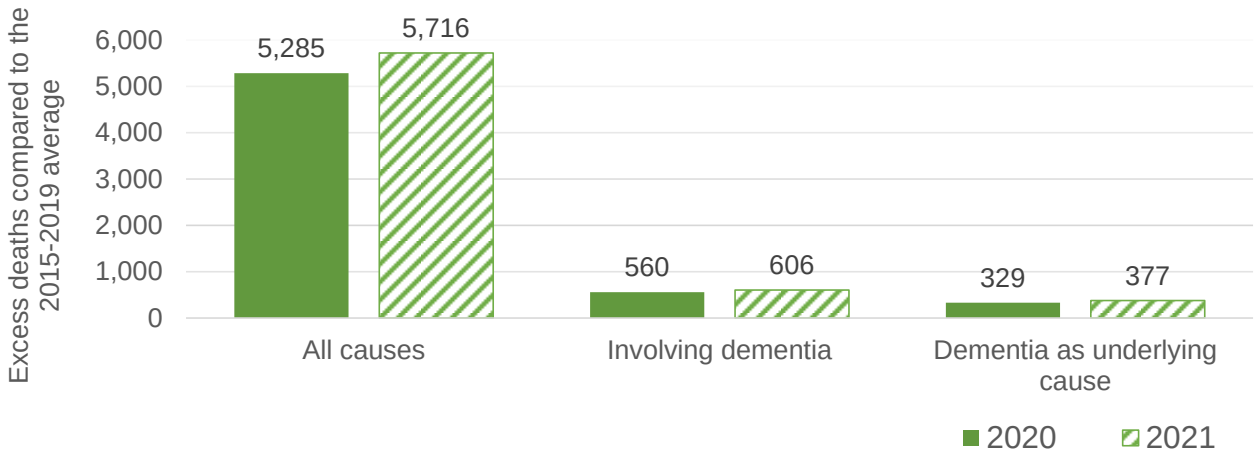
In 2021, *deaths from all causes* in hospital exceeded the 2015-2019 average by 991 deaths (+3%). In contrast, *deaths involving dementia* and *deaths with dementia as the underlying cause* were below average with -94 (-3%) and -146 (-11%) fewer deaths, respectively.

Deaths involving dementia and COVID-19, in hospital

Deaths involving dementia and COVID-19 in hospital numbered 521 in 2020 and 403 in 2021, whereas *excess deaths involving dementia* in hospital were below average for both years. This contrasts to *all cause excess deaths* in hospital, which were above average for 2021. While there is a difference in trend between *excess deaths from all causes* and *excess deaths involving dementia*, we cannot comment on reasons behind this difference due to the constraints of this analysis.

At home or in non-institutional settings, deaths from all causes, deaths involving dementia and deaths with dementia as the underlying cause are above average in 2020 and 2021

Figure 7: Annual excess deaths compared to the 2015-2019 average at home or in non-institutional settings, Scotland, 2020 and 2021



Deaths involving dementia and deaths with dementia as the underlying cause, compared with deaths from all causes, at home or in non-institutional settings

At home or in non-institutional settings in 2020, there were 5,285 (+34%) *excess deaths from all causes* compared to the 2015-2019 average. *Deaths involving dementia* and *deaths with dementia as the underlying cause* also exceeded the average with 560 (+56%) and 329 (+63%) deaths, respectively.

In 2021, *deaths from all causes* exceeded the 2015-2019 average by 5,716 (+37%). *Deaths involving dementia* and *deaths with dementia as the underlying cause* also exceeded the average with 606 (+60%) and 377 (+72%) deaths, respectively.

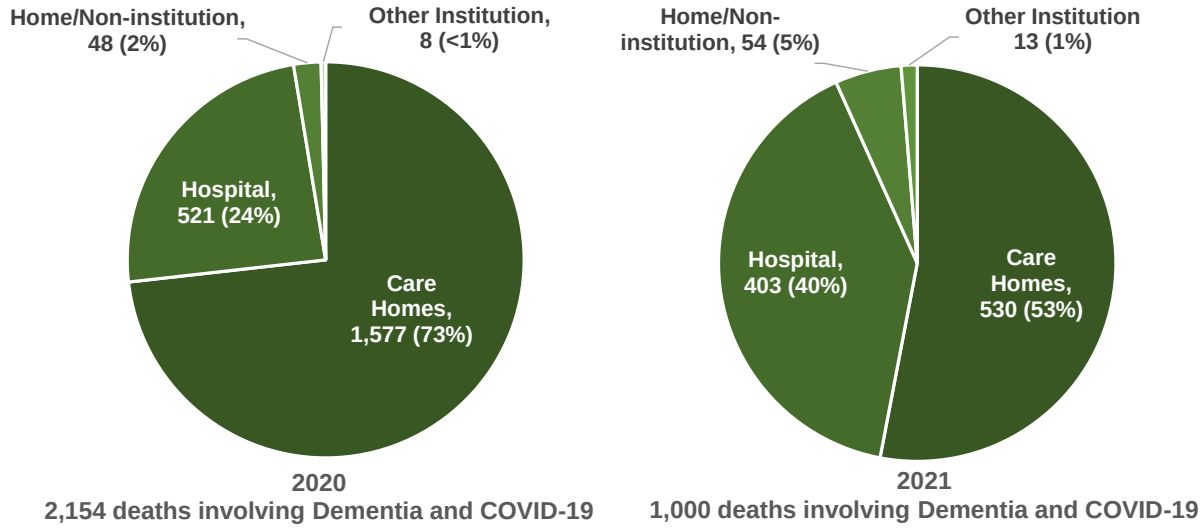
Deaths involving dementia and COVID-19 at home or in non-institutional settings

Compared to care homes and hospital settings, fewer *deaths involving dementia and COVID-19* were registered at home or non-institutional settings, with 48 deaths in 2020 and 54 deaths in 2021. This finding contrasts to the number of *excess deaths involving dementia*, which were high in both years. This suggests that the trend in elevated *excess deaths involving dementia* at home or in non-institutional settings is not due to *deaths involving COVID-19*.

However, this elevated excess is not observed in hospitals where *deaths involving dementia* are below average for 2020 and 2021. This suggests a shift in the location of death from hospitals, as well as from care homes in 2021, to home or non-institutional settings.

Between 2020 and 2021, deaths involving dementia and COVID-19 reduced proportionally in care homes and increased proportionally in hospital

Figure 8: Deaths involving dementia and COVID-19 by setting, Scotland, 2020 and 2021



Deaths involving dementia and COVID-19

Since the start of the pandemic in March 2020 until the end of March 2022 (week ending 3 April 2022) there have been 3,571 *deaths registered involving dementia and COVID-19*.

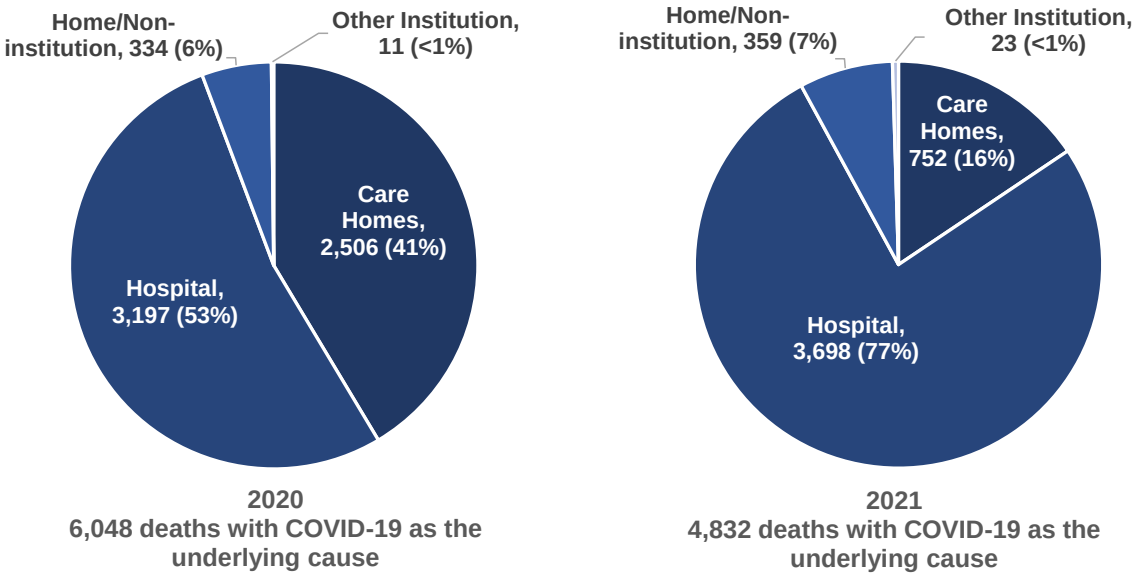
In 2020, there were 2,154 *deaths registered involving dementia and COVID-19*. Of these, only 3% were registered *with dementia as the underlying cause*. In contrast, 95% were registered *with COVID-19 as the underlying cause* (with the remaining 2% due to some other underlying cause).

In 2021, *deaths involving dementia and COVID-19* were lower at 1,000. The proportion that had *dementia as the underlying cause* increased in 2021 to 12%. 82% of *deaths involving dementia and COVID-19* were registered *with COVID-19 as the underlying cause* (with the remaining 6% due to some other underlying cause).

When considering the setting of *deaths involving dementia and COVID-19*, 73% of deaths occurred in care homes in 2020. This reduced to 53% in 2021. Conversely, 24% of *deaths involving dementia and COVID-19* occurred in hospital in 2020. This increased to 40% in 2021. This shows a shift in location of deaths across these years.

Deaths with COVID-19 as the underlying cause

Figure 9: Deaths with COVID-19 as the underlying cause by setting, Scotland, 2020 and 2021



Of the 6,048 *deaths with COVID-19 as the underlying cause* in 2020, 41% occurred in care homes. This reduced to 16% of the 4,832 *deaths registered with COVID-19 as the underlying cause* in 2021.

Conversely, the proportion of *deaths with COVID-19 as the underlying cause* that occurred in hospital in 2020 was 53%. This increased to 77% in 2021. This shows that while there were fewer *deaths with COVID-19 as the underlying cause* in 2021 than in 2020, a larger proportion occurred in hospital.

Limitations

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% (PACSIm) of people aged 65+ with dementia in Scotland receive a medical diagnosis. PACSIm 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 medical 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. While the underreporting of dementia will understate the true rate of deaths involving dementia in mortality data, this limitation should not impact on the conclusions made when comparing average deaths over recent years, since estimated diagnosis rates remain broadly the same over that time.

Excess deaths as a measure of the impact of the pandemic

The measurement of excess deaths is increasingly used to assess the impact of the pandemic. Large international studies have now been published, including analysis of global excess deaths by the World Health Organisation[3], and it is a continuously evolving picture of methodology development to understand the effects of COVID-19 on mortality within and across nations.

On methodological issues, usually the previous five years are used to compare against the most recent year to calculate excess deaths. In 2020, excess deaths were measured by comparing the 2020 figure against the average for 2015-2019. However, as excess deaths are a key measure of the effect of the pandemic, it is not appropriate to compare the 2021 figure against the 2016-2020 average as that average will be affected by the pandemic with higher deaths in Spring 2020. NRS (as well as the Office for National Statistics (ONS) and Northern Ireland Statistics and Research Agency (NISRA)) therefore decided to continue to use the 2015-2019 average to measure excess deaths in 2021.

[3] https://www.who.int/news/item/05-05-2022-14.9-million-excess-deaths-were-associated-with-the-covid-19-pandemic-in-2020-and-2021

For 2022, the excess deaths calculation would usually incorporate the mortality data for the most recent 5 year period (2017-2021). However, given the unusual nature of the 2020 data and the decision previously taken for 2021, NRS (as well as ONS and NISRA) decided to use the average of 2016, 2017, 2018, 2019 and 2021, and therefore continue to exclude 2020 from the five-year average.

The effect of an ageing population means that the five year average number of deaths used for calculating excess deaths in 2015, 2016, 2017, 2018 and 2019 (2010-2014, 2011-2015, 2012-2016, 2013-2017; 2014-2018) increased by slightly over 1% each year. Therefore, by using the 2015-2019 average in 2021, there is a risk that we have overestimated excess deaths, by not fully accounting for the ageing population.

Relevant mortality statistics have limitations, specifically when it comes to assessing disease progression and lived experiences of people with dementia and adult care home residents who are often living with dementia. While these wider issues are critical, they are out of scope for this report. The parameters and remit of the report do not extend to the identification and analysis of wider harms that may have been caused by restrictions or disruption to essential health services and care as they relate to wider health outcomes and experiences.

The analysis enables us to consider the potential reasons for the trends observed from what we know was happening across the time periods covered in this analysis. This includes the wider context of vaccination programmes, increased testing and improved understanding of COVID-19 symptoms. However, we are unable to say definitively how the wider context influenced trends in excess deaths since this analysis is statistical and necessarily retrospective. For instance, as discussed in the published analysis of ‘Excess deaths from all causes, involving and with dementia as the underlying cause: Scotland 2020/2021’, a reduction in weekly average deaths involving dementia over the course of the pandemic may relate to the peak in excess deaths caused by dementia near the beginning of the pandemic. Some of these deaths may have been caused by COVID-19 with dementia as a contributory factor; however, the involvement of COVID-19 may not have been registered on the death certificate, with dementia assumed to be the underlying cause, since testing was less widespread outside hospital settings and there was less awareness of all COVID-19 symptoms. However, the level of COVID-19 involvement in these deaths registered with dementia as the underlying cause cannot be established categorically.

In addition, we are unable to determine the potential reasons for ongoing increased levels of excess deaths at home, both involving dementia and from all causes.

Issues relating to excess deaths in care homes

Measuring longer-term trends in mortality is appropriate to reduce the impact of random variation and recording issues that may occur in the reporting of weekly

figures. In this context, it is relevant to highlight the potential impact of a fluctuating care home population, with a reduction in occupancy over time potentially influencing a reduction in excess deaths after the first wave of the pandemic.

As cited above, the estimated number of residents in care homes for older people decreased by 6%, from 32,445 to 30,502, between 2019 and 2021 (see the Public Health Scotland Care Home Census 2021). This population remained relatively stable between 2021 and 2022, with 30,552 residents in care homes for older people reported in the Public Health Scotland Care Home Census 2022, although the older adult care home population has decreased by 9% since 2012 despite an ageing population in Scotland. This reduction in occupancy may have impacted the statistics for when we have compared excess deaths between 2020 and 2021, as we would expect a lower number of deaths with reduced occupancy. Additionally, it is likely that the most vulnerable residents died earlier in the pandemic, which may have influenced the profile of residents at later stages of the pandemic i.e. to be younger and less clinically vulnerable.

Further, excess deaths is a broad measure of mortality that does not account for differences in the age of populations in different settings. For example, care homes have a population consisting of older and more clinically vulnerable individuals, and as such this population is likely to be disproportionally impacted by a virus such as COVID-19. There are also further issues related to difficulties of infection prevention in care homes, where close contact care is required, with the risk of an outbreak of COVID-19 infection increasing progressively as the size of the care home increases (see the Public Health Scotland report on discharges from NHSScotland hospitals to care homes between 1 March and 31 May 2020).

Notes on annual dementia death statistics published by NRS

The NRS report Alzheimer's disease and other dementias, published on 26 July 2022, shows that *deaths registered with dementia as the underlying cause* were 2% below[4] the 2015-2019 average in 2021 and 3% above[5] the 2015-2019 average in 2020. *Deaths registered with dementia as the underlying cause* were 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 from all causes* between 2001 and 2019 ranged from -4% to +6% (see supplementary table 5).

[4] The percentage of excess deaths may differ slightly from analysis in the current report as analysis in the NRS report is based on annual rather than weekly figures (corrected for number of days in weeks 1 and 53)

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