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**Title**

# Deaths at home, area-based deprivation and the effect of the Covid-19 pandemic: an analysis of mortality data across four nations.

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**Keywords**

Palliative care, terminal care, COVID-19, pandemics, mortality, place of death, inequalities, deprivation, socio-economic position.

**Abstract**

Background: The number and proportion of home deaths in the UK increased during the Covid-19 pandemic. It is not known whether these changes were experienced disproportionately by people from different socioeconomic groups.

Aim: To examine the association between home death and socioeconomic position during the Covid-19 pandemic, and how this changed between 2019 and 2020.

Design: Retrospective cohort study using population-based individual-level mortality data.

Setting/participants: All registered deaths in England, Wales, Scotland and Northern Ireland. The proportion of home deaths between 28th March and 31st December 2020 was compared with the same period in 2019. We used Poisson regression models to evaluate the association between decedent's area-based level of deprivation and risk of home death, as well as the interaction between deprivation and year of death, for each nation separately.

Results: Between the 28th March and 31st December 2020, 409,718 deaths were recorded in England, 46,372 in Scotland, 26,410 in Wales and 13,404 in Northern Ireland. All four nations showed an increase in the adjusted proportion of home deaths between 2019 and 2020, ranging from 21% to 28%. This increase was lowest for people living in the most deprived areas in all nations, with evidence of a deprivation gradient in England.

Conclusions: The Covid-19 pandemic exacerbated a previously described socioeconomic inequality in place of death in the UK. Further research to understand the reasons for this change and if this inequality has been sustained is needed.

**Key statements**

**What is already known about the topic?**

- Most people who express a preference say they would prefer to die at home, but there is strong evidence of socioeconomic inequality in place of death
- During the Covid-19 pandemic the number of deaths at home in the UK increased beyond the expected deaths at home for that period. It is not known if the increase in home deaths observed during the pandemic occurred equally for all socioeconomic groups

**What this paper adds**

- Home deaths increased for everyone in the UK, but the increase was greater for those living in the least deprived areas compared to those living in the most deprived areas.
- A gradient in the proportion of home deaths by area-based deprivation levels was observed in all nations but was strongest in England.

**Implications for practice, theory or policy**

- The Covid-19 pandemic has accelerated the projected increase in home deaths. If this increase is sustained services will urgently need to be restructured to cope with the increased need for community end-of-life services.
- Further research to understand the trends identified for area-based deprivation, and ongoing monitoring of this inequality, is essential.
- These findings have important implications in terms of preparedness for future demographic changes.

## Introduction

Understanding where people die is essential to ensure good quality care in the right place and at the right time. Home death is not always appropriate, and preferences for place of death may change, but most people who express a preference say they would prefer to die at home.[1, 2] A good quality of death at home requires high quality care and support in the community. Worldwide, there is consistent evidence of sociodemographic inequality in place of death.[3]

During the Covid-19 pandemic, important changes in the place of death were observed in different countries.[4-8] In the UK, there was a sustained increase in home deaths.[5] Very little is understood about the characteristics of people who died at home during the pandemic, and how they differed compared to pre-pandemic time periods. While strong evidence exists of socioeconomic inequality in outcomes relating to physical and mental health during the pandemic,[9] it is not known whether changes in the place of death observed during the pandemic were experienced disproportionately by people from different socioeconomic groups.

We aimed to examine the association between home death and socioeconomic position during the Covid-19 pandemic, and how this changed between 2019 and 2020.

## Methods

### *Design*

Retrospective population-based cohort study using individual-level mortality data from England, Wales, Scotland and Northern Ireland during 2019 and 2020. We used the STROBE Statement Checklist for cohort studies to report our findings (Appendix).

### *Data sources*

We accessed mortality data collected by the Office for National Statistics (ONS) in England and Wales, the National Records of Scotland (NRS) and the General Register Office for Northern Ireland (GRONI). Individual-level data was accessed through the ONS Trusted Research Environment for England and Wales, the Electronic Data Research and Innovation Service (eDRIS) for Scotland and the Honest Broker Service (HBS) Remote Access Portal for Northern Ireland.

### *Population*

We extracted data on all deaths in England, Wales, Scotland and Northern Ireland during 2019 and 2020. We defined the period between 28th March and 31st December 2020 as the period of study and compared it with the same period in 2019.

*Outcome*

The primary outcome in this study was the proportion of home deaths. For England and Wales, home deaths were identified from ONS communal establishment codes and place of death codes based on their technical recommendations.[10] For Scotland, home deaths were defined as 'non-institutional deaths' from the place of death information; we excluded external causes of deaths (ICD10 codes V01-Y36) from the analysis. A similar approach has been used in previous studies.[11, 12] For Northern Ireland, home deaths were identified from the place of death available in the dataset.

*Area-based deprivation*

As an indicator of socio-economic position, we used an area-level index of multiple deprivation for each of the four nations.[13, 14] We used deciles from the most recent deprivation index for each nation (2019 for England, 2019 for and Wales, 2020 for Scotland, and 2017 for Northern Ireland), and derived quintiles; group 1 represents decedents who lived in the most deprived areas, based on decedents' postcode of residence recorded in mortality data.

*Analysis*

We described the proportion of deaths that occurred at home during the whole time period, for 2019 and 2020.

We used Poisson regression models with robust standard errors to examine the risk of home death in each nation, independent of age and sex. Poisson models were most appropriate as odds ratios do not approximate to risk ratios when the probability of the outcome is high.[15] We added an interaction term between area-based deprivation category and year of death to examine the adjusted risk of home death for 2020 compared to 2019, for each category of area-based deprivation compared to the least deprived category (category 5). We plotted the simple effects, as the adjusted predicted proportion of home deaths, for each area-based deprivation category in 2019 and 2020. Models were produced separately for each nation.

**Results**

*Characteristics of the cohort*

Between 28th March and 31st December 2019, 369,764 deaths were recorded in England, 40,694 in Scotland, 24,381 in Wales and 11,928 in Northern Ireland. In 2020 during the same period, deaths increased in all nations to 409,718 in England, 46,372 in Scotland, 26,410 in Wales and 13,404 in Northern Ireland (Table 1).

As a proportion, home deaths increased between 2019 and 2020 in all four nations. Home deaths were more frequent in people younger than 65 years old and for males in all four nations (Table 1).

**Table 1. Numbers and place of deaths between 28th March and 31st December 2019-20 in England, Scotland, Wales and Northern Ireland.**

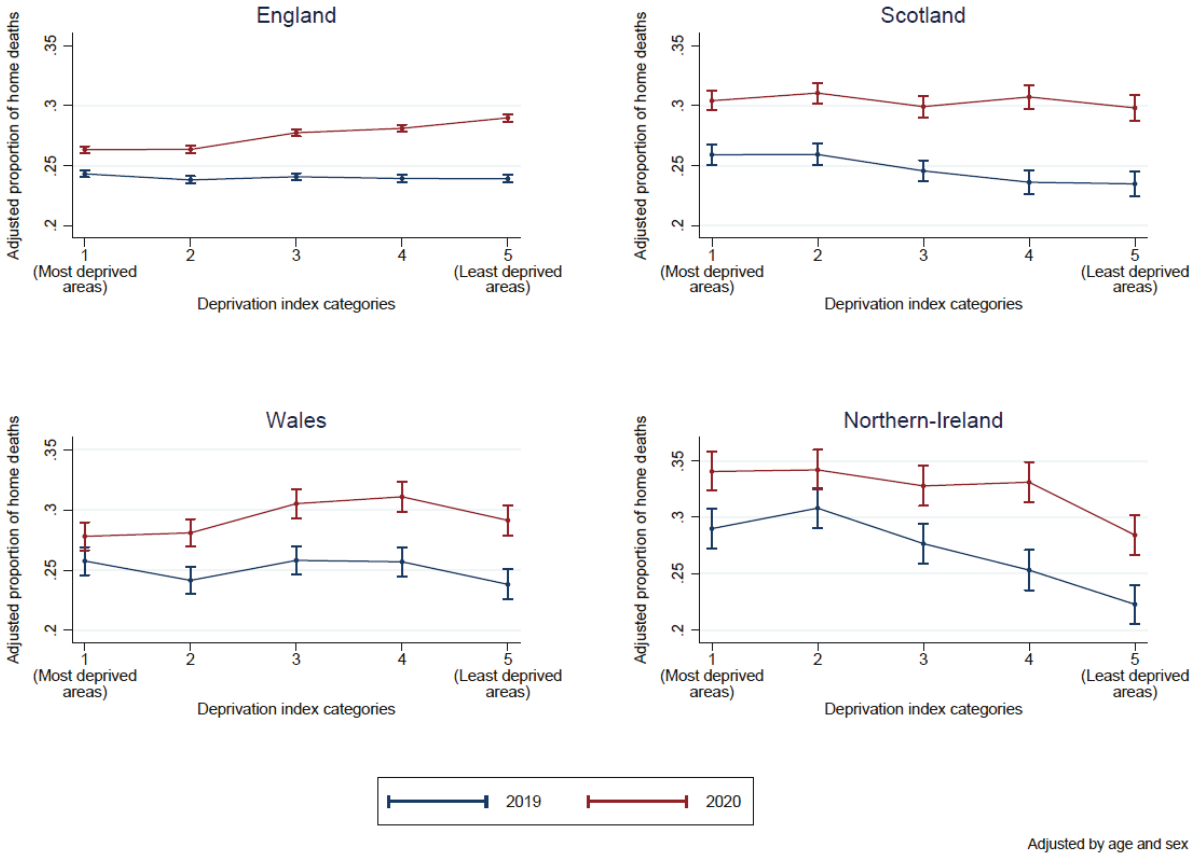
| | England | | | | | | Scotland | | | | | | Wales | | | | | | Northern Ireland | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Total | Home deaths 2019 | | Total | Home deaths 2020 | | Total | Home deaths 2019 | | Total | Home deaths 2020 | | Total | Home deaths 2019 | | Total | Home deaths 2020 | | Total | Home deaths 2019 | | Total | Home deaths 2020 | |
| | No. | No. | % | No. | No. | % | No. | No. | % | No. | No. | % | No. | No. | % | No. | No. | % | No. | No. | % | No. | No. | % |
| Total | 369764 | 91042 | 24.6 | 409718 | 113955 | 27.8 | 40694 | 10433 | 25.6 | 46372 | 14538 | 31.4 | 24381 | 6337 | 26.0 | 26410 | 7855 | 29.7 | 11928 | 3222 | 27.0 | 13404 | 4365 | 32.6 |
| Age | | | | | | | | | | | | | | | | | | | | | | | | |
| <65 | 55821 | 19059 | 34.1 | 55282 | 20326 | 36.8 | 6395 | 2396 | 37.5 | 7222 | 3294 | 45.6 | 3811 | 1388 | 36.4 | 3448 | 1422 | 41.2 | 2208 | 797 | 36.1 | 2553 | 1044 | 40.9 |
| 65-84 | 166620 | 45507 | 27.3 | 187689 | 57299 | 30.5 | 20264 | 5547 | 27.4 | 23113 | 7725 | 33.4 | 11443 | 3259 | 28.5 | 12751 | 4255 | 33.4 | 5685 | 1575 | 27.7 | 6756 | 2248 | 33.3 |
| 85+ | 147323 | 26476 | 18.0 | 166747 | 36330 | 21.8 | 14035 | 2490 | 17.7 | 16037 | 3519 | 21.9 | 9127 | 1690 | 18.5 | 10211 | 2178 | 21.3 | 4035 | 850 | 21.1 | 4095 | 1073 | 26.2 |
| Sex | | | | | | | | | | | | | | | | | | | | | | | | |
| Male | 184950 | 51102 | 27.6 | 206022 | 61930 | 30.1 | 19517 | 5711 | 29.3 | 22898 | 7851 | 34.3 | 12195 | 3576 | 29.3 | 13154 | 4271 | 32.5 | 5901 | 1725 | 29.2 | 6674 | 2332 | 34.9 |
| Female | 184814 | 39940 | 21.6 | 203696 | 52025 | 25.5 | 21177 | 4722 | 22.3 | 23474 | 6687 | 28.5 | 12186 | 2761 | 22.7 | 13256 | 3584 | 27.0 | 6027 | 1497 | 24.8 | 6730 | 2033 | 30.2 |
| Deprivation Index categories | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 (Most deprived areas) | 75873 | 19816 | 26.1 | 86090 | 23957 | 27.8 | 9538 | 2700 | 28.3 | 11163 | 3685 | 33.0 | 4898 | 1376 | 28.1 | 5289 | 1557 | 29.4 | 2416 | 729 | 30.2 | 2781 | 983 | 35.3 |
| 2 | 73668 | 18228 | 24.7 | 81715 | 22094 | 27.0 | 8935 | 2415 | 27.0 | 10353 | 3346 | 32.3 | 5047 | 1282 | 25.4 | 5608 | 1615 | 28.8 | 2445 | 759 | 31.0 | 2726 | 940 | 34.5 |
| 3 | 75891 | 18565 | 24.5 | 83590 | 23278 | 27.9 | 8674 | 2157 | 24.9 | 9515 | 2899 | 30.5 | 4990 | 1322 | 26.5 | 5334 | 1639 | 30.7 | 2404 | 646 | 26.9 | 2681 | 868 | 32.4 |
| 4 | 75121 | 18021 | 24.0 | 81970 | 22879 | 27.9 | 7259 | 1718 | 23.7 | 8228 | 2535 | 30.8 | 4921 | 1288 | 26.2 | 5185 | 1613 | 31.1 | 2320 | 580 | 25.0 | 2617 | 855 | 32.7 |
| 5 (Least deprived areas) | 69211 | 16412 | 23.7 | 76353 | 21747 | 28.5 | 6288 | 1443 | 23.0 | 7113 | 2073 | 29.1 | 4525 | 1069 | 23.6 | 4994 | 1431 | 28.7 | 2263 | 487 | 21.5 | 2534 | 702 | 27.7 |

*Home deaths and area-based deprivation*

In all nations, there was a statistically significant increase in the estimated adjusted proportion of home deaths between 2019 and 2020 (Table 1 in supplemental material). In England, the increase in the proportion of home deaths in 2020 was lower for people living in more deprived areas (IRR 0.89, 95% CI 0.87 to 0.91), with evidence of a deprivation gradient. In Scotland and Wales, there was a similar pattern though this only reached statistical significance for those living in the most deprived areas.

Figure 1 shows the age and sex adjusted proportion of home deaths by area-based deprivation category and year of death. This figure shows that in all area-based deprivation categories, the proportion of home deaths was higher in 2020 than in 2019. While the baseline (2019) pattern differed across the nations, the increase in home deaths was consistently greatest in the least deprived groups (categories 4 and 5) compared to the most deprived groups (categories 1 and 2).

**Figure 1: Age and sex adjusted proportion of home deaths by area-based deprivation category and year of death.**




**Discussion**

*Main findings/results of the study*

Across the UK, the proportion of home deaths increased in 2020 compared to 2019. However, this increase was not uniform across categories of area-based deprivation. People living in less deprived areas had a greater increase in home deaths than those living in more deprived areas, and a deprivation gradient was evident which was strongest in England.

Reasons for the observed trends are not clear. Visiting restrictions implemented in hospitals and the fear of dying in isolation,[16, 17] hospital avoidance,[18] as well as changes in the patterns of acute hospital use during the pandemic[19] might explain the increase in the proportion of home deaths overall. For those in deprived areas, poor housing conditions or limited access to community-based support may have contributed to the observed trends.[20, 21] While previous research identifies home as a frequent preference for place of death,[1, 2] we do not know whether (and how) preferences changed during the pandemic.

Differences across nations in baseline (2019) trends might be explained by factors related to health care access such as rurality, availability of services, and cultural factors that influence preferences for place of care and death. More research is needed to understand the quality of care provided to people dying at home during the pandemic, and influence of people's preferences and access to health care services on the observed trends. Additional factors such as ethnicity, geographical area and diagnosis should be investigated.

Pre-pandemic, in high-income countries people living in more deprived areas were less likely to die at home and more likely to die in hospital.[3] There is very little evidence of how inequalities in the place of death changed outside the UK during the pandemic; whether the strain on health care services during Covid-19 led to a similar pattern in home deaths inequalities outside the UK should be investigated.

The Covid-19 pandemic accelerated the projected increase in home deaths in the UK.[4] While an increase in home deaths from 24.6% to 27.8% in England might seem small in relative terms, in absolute numbers this represents 22,913 additional home deaths. Given the projected increase in deaths over the next 20 years, a substantial increase in community-based end-of-life care service provision is likely to be needed.

*Strengths and limitations of the study*

This is the first study to examine characteristics of people who died at home during pandemic, using individual level whole-population data across the four UK nations. However, there are limitations. Home deaths in Scotland were indirectly identified and therefore might be overestimated. We mitigated this by excluding external causes of death. We could not investigate the effect of ethnicity,

or the intersectionality between ethnicity and deprivation. We did not have information on preferences or quality of care at home during the pandemic, which means we cannot fully understand the reasons for these changes in home deaths. We did not adjust for cause of death, or whether the death was caused by Covid-19, since testing for Covid-19 in the community was scarce during much of 2020.

**Conclusion**

During 2020 there was exacerbation of a previously described inequality in place of death in the UK. It is recognised that when services are stretched, as they were during the pandemic, inequalities can emerge. Our data may herald widening socioeconomic inequalities in place of death over the next decades, in the UK and elsewere, as the number of people dying with palliative care needs increases. Further research to understand these trends, and ongoing monitoring, is essential.

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## Declarations

### Authorship

IJH, KES, LKF, MH and AEB had the idea for the CovPall-Connect study and applied for funding and data access. JL, JMD and KES designed the data analysis plan. Data analysis was carried out by JL and JMD with input from KES, IJH and LF. JL, JMD, AEB, MH, SB, FEMM, LKF, IJH and KES continued to interpret the data. JL wrote the first draft of the paper. JMD, AEB, MH, SB, FEMM, LKF, IJH and KES contributed to subsequent drafts and approved the final paper.

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KES is the Laing Galazka Chair in palliative care at King's College London, funded by an endowment from Cicely Saunders International and the Kirby Laing Foundation. IJH is an NIHR Senior Investigator Emeritus. FEMM is a National Institute for Health and Care Research (NIHR) Senior Investigator. IJH and SB are supported by the NIHR Applied Research Collaboration (ARC) South London (SL) and NIHR ARC East of England respectively. The views expressed in this article are those of the author(s) and not necessarily those of the NIHR, or the Department of Health and Social Care.

### Declaration of conflicts of interest

The Authors declare that there is no conflict of interest.

### Research ethics

Only anonymised data was used in this study and therefore patient consent was not required.

### Data management and sharing

The data that support the findings of this study are available from the Office for National Statistics (England and Wales mortality data), the National Records of Scotland (NRS) and the General Register Office for Northern Ireland (GRONI). Restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available.

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This work was produced using statistical data from ONS. The use of the ONS statistical data in this work does not imply the endorsement of the ONS in relation to the interpretation or analysis of the statistical data. We would like to acknowledge all members of the CovPall connect team, in particular Harry Watson and Dr Adejoke Oluyase. This work uses research datasets which may not exactly reproduce National Statistics aggregates. The authors would like to acknowledge the support of the eDRIS Team (Public Health Scotland) for their involvement in obtaining approvals, provisioning and linking data and the use of the secure analytical platform within the National Safe Haven.

The authors would like to acknowledge the help provided by the staff of the Honest Broker Service (HBS) within the Business Services Organisation Northern Ireland (BSO). The HBS is funded by the BSO and the Department of Health (DoH). 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 BSO.

**Figure 1. Age and sex adjusted proportion of home deaths by deprivation and year of death in the four nations between the 28th March to 31st December for 2019 and 2020.**