

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

Paliative Medicine 2023, Vol. 37(7) 1034–1039 © The Author(s) 2023 Article reuse guidelines: sagepub.com/journals-permissions DOI: 10.1177/02692163231167212 journals.sagepub.com/home/pmj



Javiera Leniz<sup>1,2</sup>, Joanna M Davies<sup>1</sup>, Anna E Bone<sup>1</sup>, Mevhibe Hocaoglu<sup>1,3</sup>, Julia Verne<sup>4</sup>, Stephen Barclay<sup>5</sup>, Fliss E M Murtagh<sup>1,6</sup>, Lorna K Fraser<sup>1,7</sup>, Irene J Higginson<sup>1</sup> and Katherine E Sleeman<sup>1</sup>

### 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.

### Keywords

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

#### 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.

<sup>1</sup>Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London, London, UK

<sup>2</sup>Pontificia Universidad Católica de Chile, Escuela de Medicina,

Departamento de Salud Pública, Santiago, Chile

<sup>3</sup>Harvard Medical School, Blavatnik Institute, Global Health and Social Medicine, Boston, MA, USA

<sup>4</sup>Office for Health Improvement and Disparities, Department of Health and Social Care, London, UK

<sup>5</sup>Martin House Research Centre, Department of Health Sciences, University of York, Heslington, York, UK  <sup>6</sup>Primary Care Unit, Department of Public Health and Primary Care, University of Cambridge, Cambridge, Cambridgeshire, UK
 <sup>7</sup>Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Hull, UK

#### Corresponding author:

Katherine E Sleeman, Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London, Bessemer Road, London SE5 9PJ, UK.

Email: katherine.sleeman@kcl.ac.uk

#### 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.<sup>1,2</sup> 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.<sup>3</sup>

During the Covid-19 pandemic, important changes in the place of death were observed in different countries.<sup>4–8</sup> In the UK, there was a sustained increase in home deaths.<sup>5</sup> 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,<sup>9</sup> 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 (Supplemental Appendix).

# Data sources

We accessed mortality data collected by the Office for National Statistics (ONS) in England and Wales,<sup>10</sup> the

National Records of Scotland (NRS) and the General Register Office for Northern Ireland (GRONI). Individuallevel 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.<sup>11</sup> 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.<sup>12,13</sup> 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.<sup>14,15</sup> We used deciles from the most recent deprivation index for each nation (2019 for England, 2019 for 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.<sup>16</sup> 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).

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).

	England						Scotland						Wales						Northern	Ireland				
	Total	Home	deaths	Total	Home c	deaths	Total	Home de	aths	Total	Home de	aths	Total	Home de	aths	Total	Home de	aths	Total	Home de	aths	Total	Home de	aths
	2019			2020			2019			2020			2019			2020			2019			2020		
	No.	No.	%	No.	No.	%	No.	No.	%	No.	No.	%	No.	No.	%	No.	No.	%	No.	No.	%	No.	No.	%
lei	369,764	91,042	2 24.6	409,718	113,95	5 27.8	40,694	10,433	25.6	46,372	14,538	31.4	24,381	6337	26.0	26,410	7855	29.7	11,928	3222	27.0	13,404	4365	32.6
0																								
<65	55,821	19,055	9 34.1	55,282	20,326	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
55-84	166,620	45,50;	7 27.3	187,689	57,299	30.5	20,264	5547	27.4	23,113	7725	33.4	11,443	3259	28.5	12,751	4255	33.4	5685	1575	27.7	6756	2248	33.3
35+	147,323	26,47t	5 18.0	166,747	36,330	21.8	14,035	2490	17.7	16,037	3519	21.9	9127	1690	18.5	10,211	2178	21.3	4035	850	21.1	4095	1073	26.2
Male	184,950	51,102	2 27.6	206,022	61,930	30.1	19,517	5711	29.3	22,898	7851	34.3	12,195	3576	29.3	13,154	4271	32.5	5901	1725	29.2	6674	2332	34.9
emale	184,814	39,940	J 21.6	203,696	52,025	25.5	21,177	4722	22.3	23,474	6687	28.5	12,186	2761	22.7	13,256	3584	27.0	6027	1497	24.8	6730	2033	30.2
privation index categories																								
1 (most deprived areas)	75,873	19,816	5 26.1	86,090	23,957	27.8	9538	2700	28.3	11,163	3685	33.0	4898	1376	28.1	5289	1557	29.4	2416	729	30.2	2781	983	35.3
0	73,668	18,228	3 24.7	81,715	22,094	27.0	8935	2415	27.0	10,353	3346	32.3	5047	1282	25.4	5608	1615	28.8	2445	759	31.0	2726	940	34.5
~	75,891	18,565	5 24.5	83,590	23,278	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
-	75,121	18,021	1 24.0	81,970	22,879	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)	69,211	16,412	23.7	. 76,353	21,747	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

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

Home deaths and area-based deprivation



**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.

# 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,<sup>17,18</sup> hospital avoidance<sup>19</sup> as well as changes in the patterns of acute hospital use during the pandemic<sup>20</sup> 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.<sup>21,22</sup> While previous research identifies home as a frequent preference for place of death,<sup>1,2</sup> 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.<sup>3</sup> 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.<sup>4</sup> 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.

### Acknowledgements

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.

### 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.

#### 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.

# **Declaration of conflicting interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

# Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The Better End of Life Programme is funded by Marie Curie, grant [MCSON-20-102]. This research used data assets made available as part of the Data and Connectivity National Core Study, led by Health Data Research UK in partnership with the Office for National Statistics and funded by UK Research and Innovation (CovPall-Connect study, grant ref MC PC 20029; HDRUK2020.145, Principal Investigator Professor Irene J Higginson). 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.

# **Research ethics**

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

# **ORCID** iDs

Javiera Leniz Dhttps://orcid.org/0000-0002-9315-4871 Joanna M Davies D https://orcid.org/0000-0002-6375-0023 Anna E Bone D https://orcid.org/0000-0002-8800-9581 Fliss EM Murtagh D https://orcid.org/0000-0003-1289-3726 Lorna K Fraser D https://orcid.org/0000-0002-1360-4191 Irene J Higginson D https://orcid.org/0000-0002-3687-1313 Katherine E Sleeman D https://orcid.org/0000-0002-9777-4373

### Supplemental material

Supplemental material for this article is available online.

### References

1. Higginson IJ, Gomes B, Calanzani N, et al. Priorities for treatment, care and information if faced with serious illness: a comparative population-based survey in seven European countries. *Palliat Med* 2014; 28: 101–110.

- Hoare S, Morris ZS, Kelly MP, et al. Do patients want to die at home? A systematic review of the UK literature, focused on missing preferences for place of death. *PLoS ONE* 2015; 10: e0142723.
- 3. Davies JM, Sleeman KE, Leniz J, et al. Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. *PLoS Med* 2019; 16: e1002782.
- 4. Bone AE, Finucane AM, Leniz J, et al. Changing patterns of mortality during the COVID-19 pandemic: Populationbased modelling to understand palliative care implications. *Palliat Med* 2020; 34: 1193–1201.
- O'Donnell SB, Bone AE, Finucane AM, et al. Changes in mortality patterns and place of death during the COVID-19 pandemic: a descriptive analysis of mortality data across four nations. *Palliat Med* 2021; 35: 1975–1984.
- Strang P, Fürst P and Schultz T. Excess deaths from COVID-19 correlate with age and socio-economic status. a database study in the Stockholm region. Ups J Med Sci 2020; 125: 297–304.
- Nomura S, Eguchi A, Ghaznavi C, et al. Excess deaths from non-COVID-19-related causes in Japan and 47 prefectures from January 2020 through May 2021 by place of death. SSM Popul Health 2022; 19: 101196.
- Panattoni LE, McDermott CL, Li L, et al. Effect of the COVID-19 pandemic on place of death among medicaid and commercially insured patients with cancer in Washington State. *J Clin Oncol* 2023; 41: 1610–1617.
- Marmot M, Allen J, Goldblatt P, et al. Build Back Fairer: The COVID-19 Marmot Review, https://www.health.org. uk/publications/build-back-fairer-the-covid-19-marmotreview (2020 accessed 7 February 2023).
- Office for National Statistics, released 22 August 2022, ONS SRS Metadata Catalogue, dataset, Death Registrations Finalised - England and Wales, DOI: 10.57906/ jygg-zn40
- 11. England PH. Classification of place of death. A technical bulletin from the National End of Life Care Intelligence

Network, https://fingertips.phe.org.uk/ (2019 accessed 7 February 2023).

- 12. Black H, Waugh C, Munoz-Arroyo R, et al. Predictors of place of death in South West Scotland 2000-2010: Retrospective cohort study. *Palliat Med* 2016; 30: 764–771.
- 13. Finucane AM, Bone AE, Evans CJ, et al. The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision. *BMC Palliat Care* 2019; 18: 112.
- Payne RA and Abel G. UK indices of multiple deprivation a way to make comparisons across constituent countries easier. *Health Statist Q* 2012; 52: 22–37.
- Abel GA, Barclay ME and Payne RA. Adjusted indices of multiple deprivation to enable comparisons within and between constituent countries of the UK including an illustration using mortality rates. *BMJ Open* 2016; 6: e012750.
- Zou G. A modified poisson regression approach to prospective studies with binary data. *Am J Epidemiol* 2004; 159: 702–706.
- 17. Life Lines Team c. Restricted family visiting in intensive care during COVID-19. *Intensive Crit Care Nurs* 2020; 60: 102896.
- Rose L, Yu L, Casey J, et al. Communication and virtual visiting for families of patients in intensive care during the COVID-19 pandemic: a UK National Survey. Ann Am Thoracic Soc 2021; 18: 1685–1692.
- 19. Wakam GK, Montgomery JR, Biesterveld BE, et al. Not dying alone modern compassionate care in the Covid-19 pandemic. *N Engl J Med* 2020; 382: e88.
- Reschen ME, Bowen J, Novak A, et al. Impact of the COVID-19 pandemic on emergency department attendances and acute medical admissions. *BMC Emerg Med* 2021; 21: 143.
- 21. Mitchell S, Oliver P, Gardiner C, et al. Community end-of-life care during the COVID-19 pandemic: findings of a UK primary care survey. *BJGP Open* 2021; 5(4): BJGPO.2021.0095. https://doi.org/10.3399/BJGPO.2021.0095
- 22. Rowley J, Richards N, Carduff E, et al. The impact of poverty and deprivation at the end of life: a critical review. *Palliat Care Soc Pract* 2021; 15: 1–19.