Better End of Life Research Report, July 2022

Fairer Care at Home

The covid-19 pandemic: a stress test for palliative and end of life care in England

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Executive summary

Where people die, and the quality of care that they receive towards the end of life, matters. Understanding patterns of where people die is essential to support health policies, resource allocation, and planning and commissioning of services. This is especially important right now because of the major shifts in place of care and death during the pandemic, and the underlying trends in population ageing which mean that deaths (and therefore palliative care needs) will increase substantially over the next 20 years.

Inequalities in where people die have been well described. In many high-income countries, people who live in more deprived areas are more likely to die in hospital, and less likely to die in hospices. Since the start of the covid-19 pandemic, there has been a sustained increase in the proportion of people dying at home across the UK. The reasons for this are unclear. How the pandemic has changed inequalities relating to the place of death is not known, but is essential to guiding the planning of care and ensuring services are fit for the future. We need to know if inequalities have changed and, if so, how.

This is the second report from the Better End of Life programme. The Better End of Life programme is a collaboration between Marie Curie, King's College London Cicely Saunders Institute, Hull York Medical School, the University of Hull, and the University of Cambridge. We used routinely collected data to explore whether the pandemic uncovered (or amplified) deprivation-related inequalities in the place of death in England.

Key findings

The number and proportion of people who died at home in England from March to December 2020 increased in comparison to 2019, for both men and women. Deaths at home increased for all deprivation groups; however, this increase was greatest for people living in the least deprived areas and smallest for people living in the most deprived areas. This is important because it suggests exacerbation of a known inequality during the pandemic.

This inequality was most apparent for people who died between the first two pandemic waves (rather than in the first wave). This was a period of relatively stable mortality levels with fewer covid-19 deaths, which suggests a change that may be sustained beyond the pandemic.

The association of increased deaths at home with lower deprivation was not present for deaths where covid-19 was listed as a cause of death. This suggests that the changes observed were not a direct consequence of covid-19 infection, but resulted instead from indirect consequences of the pandemic, such as changes to the way people accessed services and disruption to the health and care system.

Rashmi Kumar, PPI member, reflects on the findings of this report

My mother sadly passed away during the pandemic. During her last months of life I was advised again and again by 111 services that I should take my mother to hospital, to A&E, if I needed support. However, having been in hospital previously, her preference was to stay at home. It was only with the support and guidance of my two nieces, who are both doctors, that we were able to look after my mother at home.

This report identifies the urgent need for investment in community care. Unless this is done quickly, it will be too late for too many people and families. More people will continue to suffer, health inequalities will widen, and the mental health impact of bereavement will get worse. Change is needed now, not in years. Lives are being lost today, and communities are suffering in silence.

Future priorities

In this report we provide the first evidence that the increase in deaths at home that occurred during the pandemic was accompanied by a widening of socioeconomic inequality. We call for:

Investment in primary care, community and palliative care services, to ensure high quality and equitable care at the end of life to meet the growing demand for these services

Everyone should have the opportunity to receive the best possible care at the end of life, in the place of their choosing. To ensure good quality of care at home, investment in primary care, community and palliative care services is needed. We must do this in a way that reduces rather than exacerbates inequalities. Ongoing monitoring of place of death trends and inequalities is essential.

Embedding of outcome measures to drive learning and improvement

Understanding the quality of end of life care across settings is essential to guide resources and support. Routine collection and monitoring of outcomes data that is meaningful for those approaching the end of life should be implemented to identify unmet patient and carer/family needs and concerns. Linkage to nationally collected health and mortality data would be transformative for monitoring inequalities and improving the quality of care.

Investment in multi-disciplinary research to further understanding and improvement

More research is needed to understand how the lasting effects of the pandemic have shaped experiences for dying patients and their carers, in particular quality of care and whether individuals' preferences have been met. Investigating the mechanisms driving the increase in deaths at home, widening inequality, and exploring factors such as ethnicity, housing quality, social support and finances, is essential to inform delivery of effective and equitable services, fit for the future.

Introduction

The circumstances in which people are born, live, work and age are known to affect health and care outcomes (1). Health is closely linked to income, education, ethnicity and area of residence. Understanding these factors is essential when planning equitable health and care services.

The 2020 Marmot report 'Build Back Fairer' highlighted the disproportionate effect that the covid-19 pandemic had on social and economic groups(2). Individuals living in areas of high deprivation, with poor housing conditions, and those from Black, Asian and minority ethnic groups were more likely to die from covid-19. The 2020 Marmot report argued that the pandemic had exposed the underlying inequalities in society, and amplified them. The report considered the impact of the pandemic on mortality, and physical and mental health, but not on end of life care.

Understanding where people die, and the drivers of this, is essential to support health policies, resource allocation, and planning and commissioning of services. This is increasingly important right now because of the major shifts in place of care and death during the pandemic(3), and the underlying trends in population ageing, which mean that deaths (and therefore palliative care needs) will increase substantially over the next 20 years(4, 5). This will have notable implications for formal service provision as well as informal (unpaid) care.

Understanding where people die is also important because many people who express a preference say that they would prefer to die at home(6), though other aspects of care can be more important(7). In addition, preferences can change and may be influenced by social circumstances, such as income, ethnicity, housing and social support. Without adequate care and support, deaths at home may not be a positive experience.

Inequalities in where people die have been well described globally(8). In England and Wales, people who live in more deprived areas are more likely to die in hospital, and less likely to die in hospices(9, 10, 11). Less is known about inequalities in where people die in Scotland or Northern Ireland. Since the start of the covid-19 pandemic, there has been a sustained increase in the proportion of people dying at home(3). We know little about what has driven this, though there is some evidence that fears of infection and visiting restrictions contributed to more people remaining at home to die(12). Whether the pandemic uncovered (or amplified) inequalities relating to the place of death is not known.

The report uses mortality data for England to ask *"Did the pandemic uncover (or amplify) inequalities relating to the place of death?"*, and *"What are the implications for research, and health and care policy?"*.

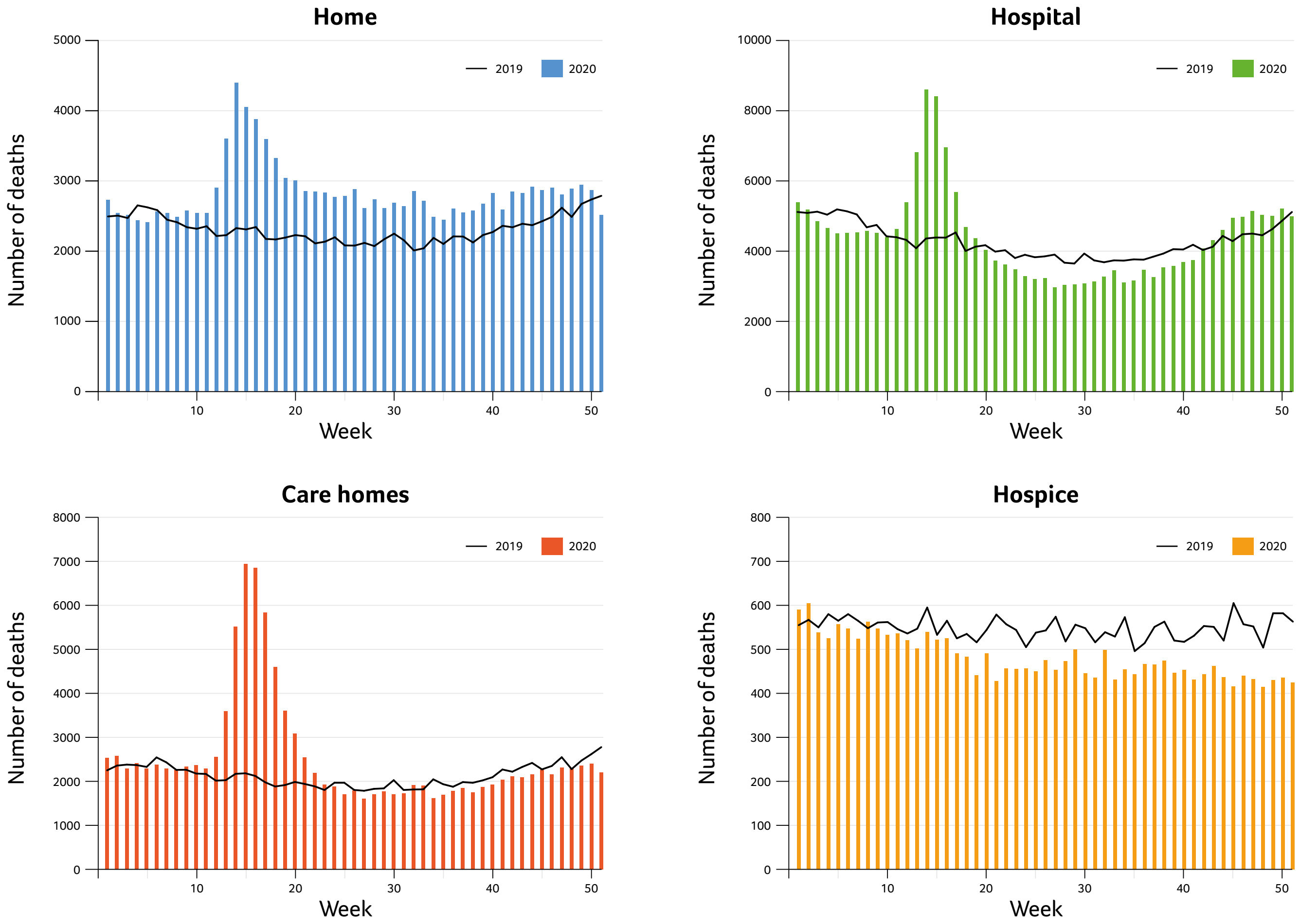
Changes in place of death during 2020 in England

We included 535,325 deaths that occurred during 2020 in England; overall 27.0% of these were at home. Figure 1 shows place of death during 2020, and compares this with baseline data from 2019.

During the first wave of the covid-19 pandemic (weeks 14 to 23 of 2020), there was an increase in the weekly number of deaths at home, in hospital and in care homes compared to 2019 baseline levels. Care home deaths subsequently fell to baseline level whilst hospital deaths fell below baseline levels. However, deaths at home remained higher than baseline levels for the duration of 2020.

Figure 1. Number of deaths by week and place of death in England 2019-20

**note, the scales vary*



METHODS BOX

Mortality data were provided by the Office for National Statistics (ONS), accessed through the ONS Trusted Research Environment. We used data on deaths in 2019 and 2020. We defined the first wave as from 28 March to 30 May 2020 and the inter-wave period from 31 May to 17 October 2020(13). We used the postcode from the decedent's place of residence to link to level of deprivation using the Index of Multiple Deprivation (IMD) for England (2019) in quintiles. Observations with a missing value for postcode were removed. Place of death was classified as home, hospital, care home and hospice. We obtained information on covid-19 related deaths using ICD-10 codes U07, U09 or U10. We used Poisson regression models with robust standard errors to report the proportion of deaths at home for each IMD group, adjusted by age and sex.

Deaths at home during 2020 in England

To understand how deaths at home changed during the first pandemic wave, and the months after it, we extracted data on all deaths in England between 28 March and 31 December 2020 and compared to baseline (2019).

- Between 28 March and 31 December 2020 there were 409,718 deaths. Overall the number and proportion of deaths at home in 2020 was higher than for the same time period in 2019 (91,042 or 24.6% in 2019; 113,955 or 27.8% in 2020) (Table 1).
- The proportion of people dying at home in 2020 was higher than in 2019 for both men and women.
- The proportion of people dying at home in 2020 was higher than in 2019 for all deprivation groups, with the largest absolute difference in the least deprived group.
- 3,566 (4.8%) of deaths where covid-19 was mentioned on the death certificate were at home

Table 1: Characteristics of people who died at home in England between 28 March and 31 December 2019-20

	28 March to 31 December 2019			28 March to 31 December 2020		
	Total number deaths	Deaths at home n	Deaths at home %	Total number deaths	Deaths at home n	Deaths at home %
Total	369,764	91,042	24.6%	409,718	113,955	27.8%
Age (mean, sd)	75.0 (15.0)			76.5 (13.8)		
Sex						
Male	184,950	51,102	27.6%	206,022	61,930	30.1%
Female	184,814	39,940	21.6%	203,696	52,025	25.5%
Deprivation (IMD)						
1 (most deprived)	75,873	19,816	26.1%	86,090	23,957	27.8%
2	73,668	18,228	24.7%	81,715	22,094	27.0%
3	75,891	18,565	24.5%	83,590	23,278	27.9%
4	75,121	18,021	24.0%	81,970	22,879	27.9%
5 (least deprived)	69,211	16,412	23.7%	76,353	21,747	28.5%
Covid-19 on death certificate						
No				335,126	110,389	32.9%
Yes				74,592	3,566	4.8%

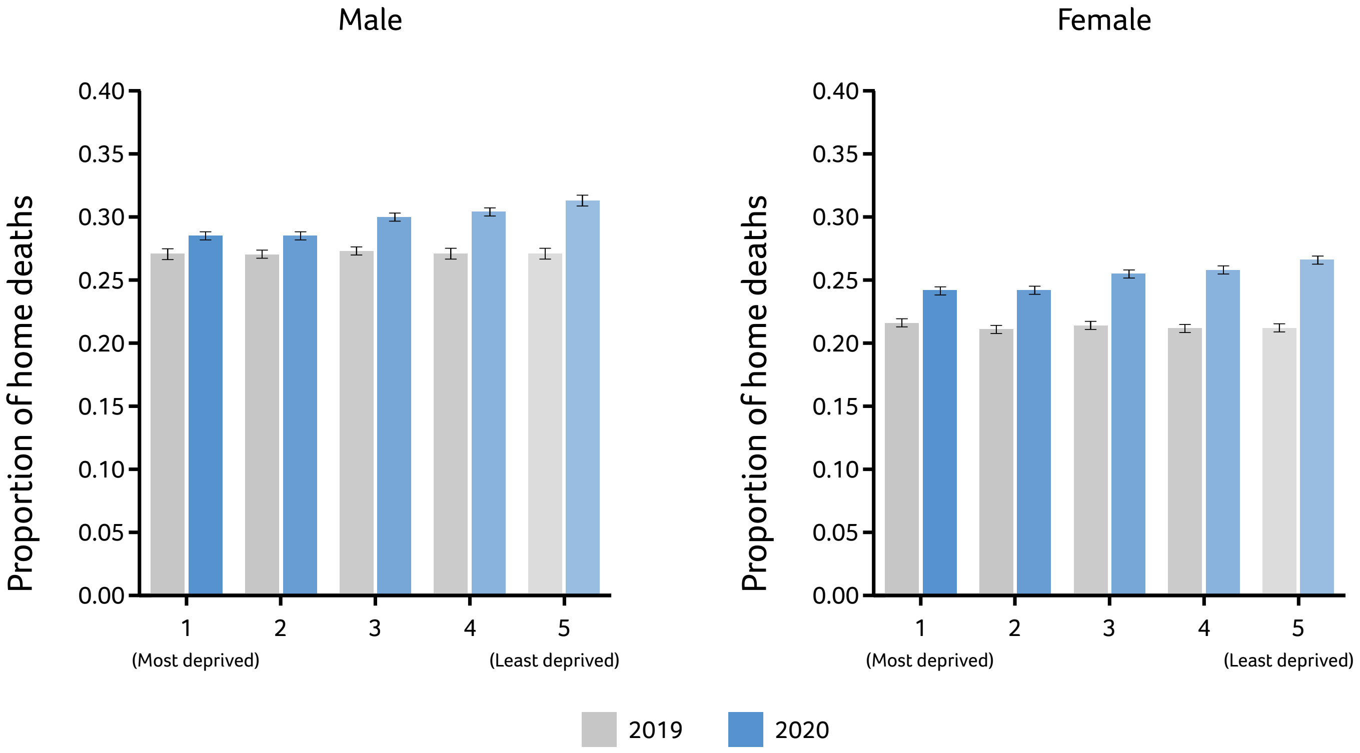
The association of socioeconomic position with deaths at home

To compare the proportion of deaths at home by level of deprivation, data were adjusted by age and sex (see Methods box).

- In 2019, the adjusted proportion of deaths at home was similar for those living in the most and least deprived areas (Figure 2). The adjusted proportion of men dying at home was higher than for women.
- During 2020 there were two main changes: first, deaths at home increased across all deprivation groups, similarly for men and women. Second, a trend emerged showing that the most deprived groups experienced the smallest increase in deaths at home, and the least deprived groups experienced the biggest increase in deaths at home.

Figure 2. Adjusted proportion of deaths at home by deprivation and sex in England

Deaths between 28 March and 31 December in 2019 and in 2020. Deprivation was derived using quintiles from the Index of Multiple Deprivation (IMD) for England



Adjusted by age

KEY MESSAGE

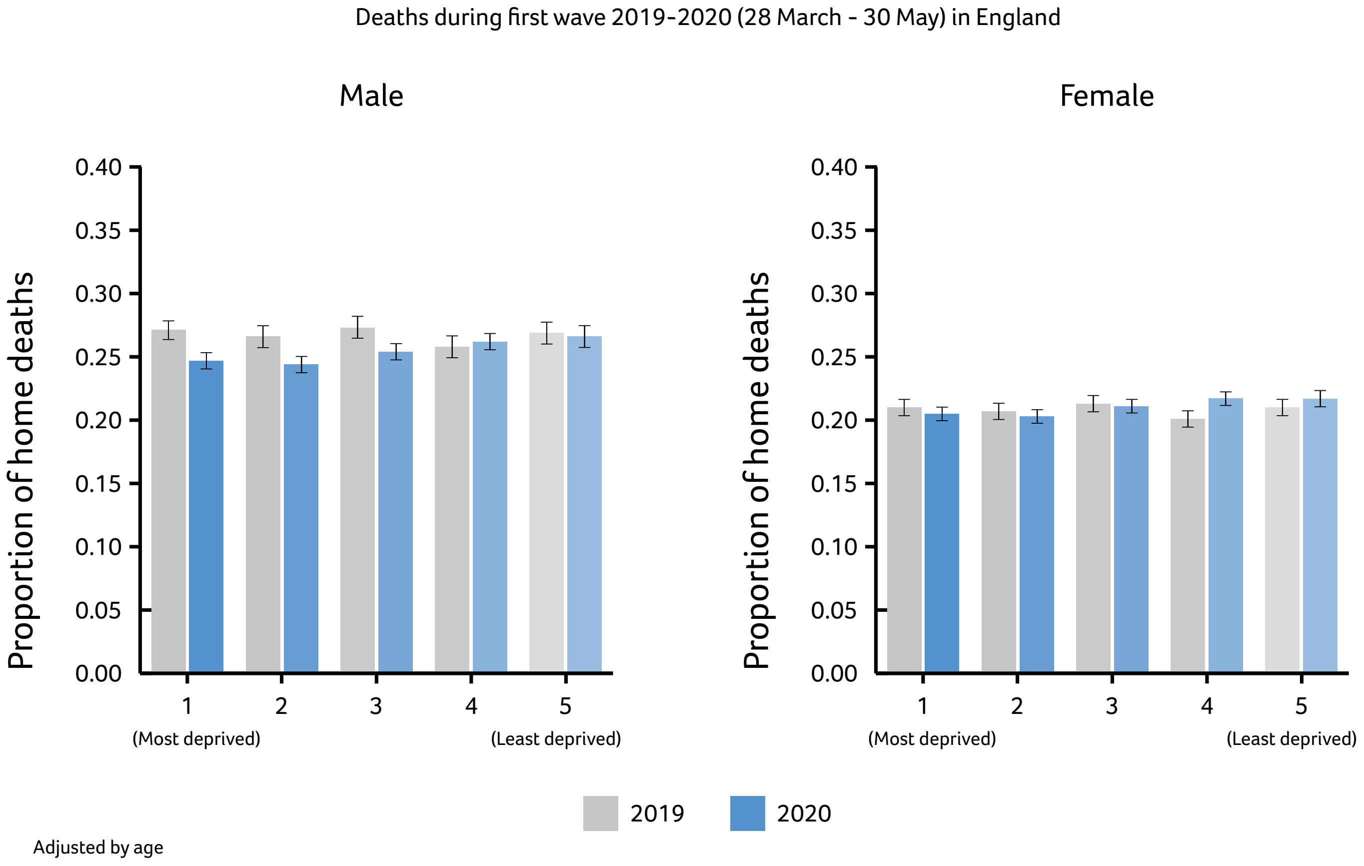
While home deaths increased during the covid-19 pandemic across all deprivation groups, the increase was smallest for people in the most deprived groups and greatest for people in the least deprived groups. This indicates that a known inequality was amplified during the pandemic.

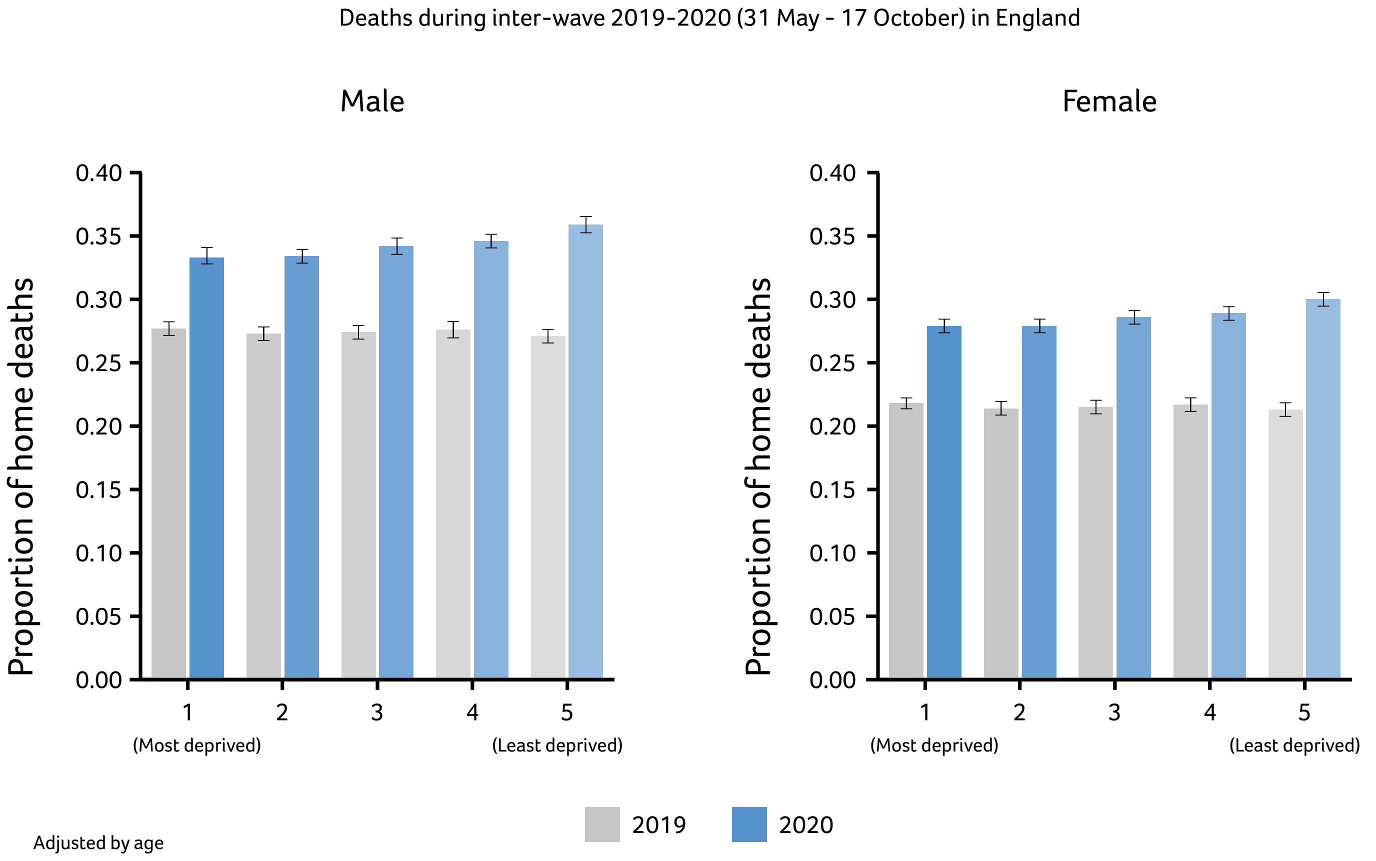
We were interested in understanding differences between the first wave of the pandemic (when numbers of deaths increased sharply across most settings) and the inter-wave period (when deaths in hospital and care homes fell to pre-pandemic levels, but there was a sustained increased in deaths at home). The inter-wave period is important to examine because it is likely to be most relevant to service and support needs post-pandemic.

- Separating the data into these two time periods revealed important differences in the relationship between deprivation and deaths at home (Figure 3). During the first wave of the pandemic, there were only small differences in the proportion of deaths at home between deprivation groups. In contrast, during the inter-wave period there were striking changes in deaths at home compared to the equivalent period in 2019; the proportion of deaths at home increased across all deprivation groups, with the greatest increase among those in the least deprived groups and the smallest increase among those in the most deprived groups.

Figure 3. Adjusted proportion of deaths at home by deprivation and sex, for first wave and inter-wave period in England

Deaths in 2019 and 2020 during first wave (28 March to 30 May) and inter-wave period (31 May to 17 October)
Deprivation was derived using quintiles from the Index of Multiple Deprivation (IMD) for England





KEY MESSAGE

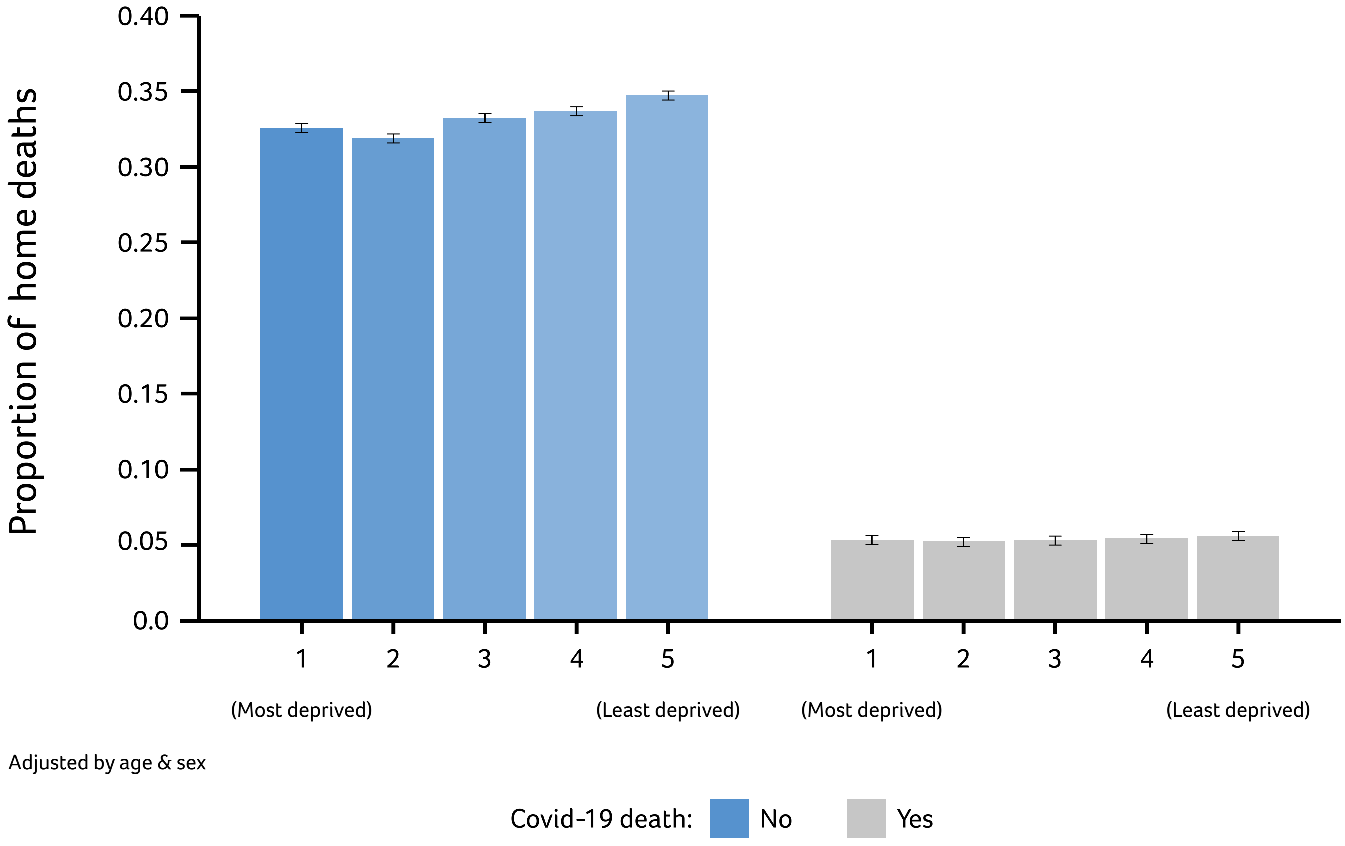
The identified socio-economic inequality in deaths at home was greatest in the inter-wave period. This is important because this was a period of stable mortality levels and few covid-19 deaths, and may therefore be more likely to reflect changes that will be sustained beyond the pandemic.

We also wanted to understand the relationship between deprivation and deaths at home, according to whether or not covid-19 was mentioned on the death certificate.

- A small proportion of people who had covid-19 on their death certificate died at home (Figure 4). We found no deprivation trend in the population where covid-19 was mentioned as a cause of death.

Figure 4. Adjusted proportion of deaths at home by deprivation and covid-19 deaths

Deaths between 28 March and 31 December 2020. Deprivation was derived using quintiles from the Index of Multiple Deprivation (IMD) for England



KEY MESSAGE

The identified socioeconomic inequality in deaths at home was not apparent among cases where covid-19 was mentioned as a cause of death, suggesting it was an indirect consequence of changes that happened during the pandemic period, rather than a direct consequence of covid-19 infection. However, community testing was scarce during the early pandemic, meaning this finding should be interpreted cautiously.

Conclusions

The 2020 Marmot report ‘Build Back Fairer’ showed that the covid-19 pandemic had *exposed the underlying inequalities in society, and amplified them*, but did not examine inequalities relating to end of life care. We show that the covid-19 pandemic exposed and amplified a known inequality relating to the place of death in England, with deaths at home increasing least among people in the most deprived groups and most among people in the least deprived groups. This pattern was especially apparent during the inter-wave period, indicating that it may herald changes that are sustained beyond the pandemic.

We cannot determine from our data why this inequality exists. Policy and health service changes, as well as preferences to avoid hospice or hospital admission (because of fears of infection and visiting restrictions), are likely to have contributed to the increase in deaths at home overall. It may be that people in the most deprived groups did not always have the necessary resources (such as appropriate housing, social support, financial security, primary care and community services) to support death at home. Further research, including qualitative research to explore people’s experiences, is needed to understand why this inequality exists, as well as the interaction with other factors such as rurality, social support, and housing quality. Data on ethnicity was not available for our analysis, but should be included where possible in future research. Understanding how preferences and quality of care changed during the pandemic is also essential.

When health services are under strain, inequalities emerge and people who are more deprived are often disadvantaged(1). We know that deaths and palliative care needs are projected to increase rapidly over the next 20 years across the UK(4, 5). Better resourcing of community health and care services is urgently needed. This includes specialist palliative care services, which enable deaths at home and improve quality of care at the end of life, as well as primary care and social care services(12, 14, 15). Ongoing monitoring of place of death trends and inequalities is essential.

Where people die, and the quality of care that they receive, matters. Everyone approaching the end of their life, regardless of their socioeconomic circumstances, should have the care and support they need, in the place of their choosing. The pandemic was a ‘stress-test’ for palliative and end of life care. Population ageing means that without better resourcing of services, the inequality that emerged during the covid-19 pandemic could increase. The data in this report calls for careful attention to ensure care and support for people approaching the end of life that is equitable, tailored to their needs and preferences, and fit for future demographic changes.

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Appendix

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