Advance Care Planning and Place of Death During the COVID-19 Pandemic: A Retrospective Analysis of Routinely Collected Data

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Abstract

Increased advance care planning was endorsed at the start of the Coronavirus disease 2019 (COVID-19) pandemic with the aim of optimizing end-of-life care. This retrospective observational cohort study explores the impact of advanced care planning on place of death. 21,962 records from patients who died during the first year of the pandemic and who had an Electronic Palliative Care Coordination System record were included. 11,913 (54%) had a documented place of death. Of these 5,339 died at home and 2,378 died in hospital. 9,971 (45%) had both a documented place of death and a preferred place of death. Of these, 7,668 (77%) died in their preferred location. Documented elements of advance care planning, such as resuscitation status and ceiling of treatment decisions, were associated with an increased likelihood of dying in the preferred location, as were the number of times the record was viewed. During the COVID-19 pandemic, advanced care planning and the use of digital care coordination systems presented an opportunity for patients and healthcare staff to personalize care and influence end-of-life experiences.

Keywords

palliative care, COVID-19, advance care planning, place of death, DNACPR, ceiling of treatment, communication, end-of-life, electronic palliative care coordination system

Key Findings

1. 77% of people with a Coordinate My Care record with both a recorded place of death and a recorded preferred place of death died in their preferred location.
2. Less than one-fifth of individuals did not record a preferred place of death. Of these, a higher proportion died in hospital compared to those who did record a preferred place of death.
3. Documented elements of advance care planning such as resuscitation status, and ceiling of treatment decisions were associated with an increased likelihood of dying in the preferred place.
4. A lower socio-economic status was associated with a reduced likelihood of dying in the preferred place.

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Background

Advance care planning involves dynamic discussions during which patient-specific goals and preferences are identified to try and ensure that end-of-life care aligns accordingly.[1,2] Accessible, up-to-date documentation of end-of-life preferences, through digital means such as Electronic Palliative Care Coordination Systems, is fundamental to this process.[3]

Place of death, and dying in the preferred place of death, are widely used as quality indicators for end-of-life care.[4,5] Most people who express a preference say that they would prefer to die in their usual place of residence (home/care home) and most patients would not choose to die in hospital.[6–8] Therefore, dying in a hospital and dying in a location that is not in keeping with individual patient preference can be considered factors contributing to poor end-of-life patient experiences and outcomes. Some people, however, do express a preference to die in hospital and others might actively choose to not express a preference.[6–10]

The Coronavirus disease 2019 (COVID-19) pandemic resulted in marked increases in excess deaths and an unprecedented impact on global health service delivery.[11,12] In England during this time, more people died at home, and this trend has continued.[11] During the pandemic, advance care planning was widely advocated by clinicians and policymakers to improve patient-centered care and support end-of-life care coordination.[2,13–16] Prior to COVID-19, advance care planning has been shown to reduce unnecessary emergency hospital admissions and increase the likelihood of an individual dying where they want to die.[10,17–19] Little evidence has been published to date, however, about the relationship between advance care planning and place of death during the COVID-19 pandemic. The aim of this study was to describe the impact of advance care planning on the place of death during the COVID-19 pandemic using routinely collected data from an Electronic Palliative Care Coordination System.

Methods

Study Design, Setting and Participants

This is a retrospective observational cohort study of Coordinate My Care records for people aged 18+, who had consented to their data being anonymously analyzed for research and who died during the COVID-19 pandemic, between March 3, 2020 to March 5, 2021.

Coordinate My Care is a digital communication platform developed to support advance care planning for patients with complex, life-limiting conditions. It is the largest Electronic Palliative Care Coordination System in England, commissioned in London 2010 to 2022.[20] Once published, plans can be viewed and updated by patients, primary, and acute care services, including urgent care (NHS 111, 999) providers. Records contain individuals' clinical and demographic information, as well as their wishes and preferences for care, including listing preferences for the setting of their care and place of death.[21] Coordinate My Care is integrated with the National Health Service central IT infrastructure "Spine" which allows health and social care information to be shared securely and enables alignment of key data such as date of death. Information on a persons' actual place of death is reliant on a healthcare professional manually updating individual patient record data.

Data Analysis

The study population was described using descriptive statistics in terms of patient demographic, socio-economic and clinical characteristics, documented elements of advance care planning (such as cardio-pulmonary resuscitation status, ceiling of treatment, and preferred place of death) and the total number of times that the records were viewed by urgent and nonurgent care services within the 30 days before death. Records without a recorded actual place of death and preferred place of death were also examined.

Forced multivariable logistic regression was used to develop models of factors associated with the co-primary endpoints:

- *Death in the preferred location*. Where preferred place of death matched actual place of death. Individuals who did not have both a recorded preferred place of death and a known place of death were excluded.
- *Death in hospital*. All records with a recorded place of death were included.

All factors believed to be associated a priori were included in the final model.[8,22] Geographical location (based on Clinical Commissioning Group, clinically lead local area organizations tasked with delivering NHS services during the study time period), timing within the first year of the pandemic (stratified by surges/waves in COVID-19 cases indicated by Public Health England Data [23]), and time between record creation and death (days) were also included in the models. The postcode from the patient's place of residence was used to calculate the index of multiple deprivation (IMD) for England as a marker of socio-economic status. IMD represents a combined measure of deprivation based on seven domains, each reflecting different aspects of deprivation experienced by individuals living in an area. These areas are classified into quintiles with IMD Quintile 1 representing areas with the highest deprivation and Quintile 5 areas with least deprivation.[24]

Data were analyzed using STATA v16 (StataCorp). The 95% confidence intervals which do not overlap the null value (odds ratio [OR] = 1) were considered statistically significant.[25] Data were reported according to the RECORD guidelines.[26]

Regulatory and Ethics Committee Approval

This study was approved by NHS Health Research Authority (Integrated Research Application System reference 294940). The research was exempt from NHS Research Ethics Committee review as it involved the secondary use of anonymized data collected in the course of normal care.[27]

Results

In total, 21,962 people with a Coordinate My Care record died during the study period Table 1. Most individuals were aged over 80 (67.5%, n = 14,822), with a WHO performance status of 4, indicating they were completely confined to bed or chair, unable to carry out any self-care and reliant on others for their care needs (57.0%, n = 12,512).

The majority of individuals (85.5%, n = 18,799) had a "Do Not Attempt Cardio-Pulmonary Resuscitation" recommendation recorded which had been discussed with the patient (67.2%, n = 14,678) and their family (74.3%, n = 16,317).

Most individuals wanted to be cared for and die in their usual place of residence (home/care home, 86.0%, n = 18,890 and 71.7%, n = 15,75, respectively). In total, 2.1% (n = 454) wanted to die in hospital. In total, 19.5% (n = 4295) did not record a preference for place of death.

Overall, 54.4% (n = 11,913) had a documented place of death. Of these 5339 (44.8%) died at home and 2378 (20.0%) died in hospital. In total, 45.4% (n = 9971) of all the records had both a documented place of death and preferred place of death. Of these, 76.9% (n = 7668) died in their preferred place of death and 16.3% (n = 1621) died in hospital. In total, 31.8% (n = 757) of those who died in hospital did not record a preferred place of death.

Individuals who did not have an actual place of death documented on Coordinate My Care (45.8%, n = 10,049) were more likely to live in a care home (65.7%, n = 6600 vs 27.9%, n = 3319 of those with a recorded place of death), and less likely to have a cancer diagnosis (26.1%, n = 2,621 vs 41.5%, n = 4948) (Appendix II). A smaller proportion of records for the individuals without a recorded place of death were viewed by urgent and nonurgent clinical services.

In the multivariate regression modeling, dying in the preferred location [Figure 1A] was associated with a "Do Not Attempt Cardio-Pulmonary Resuscitation" status (OR: 1.51, confidence interval [CI] 1.17-1.93), a Ceiling of Treatment for "Symptomatic Treatment" (OR: 3.52, CI 2.77-4.50), documented family discussions regarding resuscitation status (OR: 1.51, CI 1.33-1.72) and at least two nonurgent care record views in the 30 days before death (OR: 1.27, CI 1.13-1.43).

The same variables were found to be associated with a decreased likelihood of dying in hospital [Figure 1B]: "Do Not Attempt Cardio-Pulmonary Resuscitation" status (OR: 0.6, CI 0.49-0.74), a Ceiling of Treatment for "Symptomatic Treatment" (OR 0.23, CI 0.18-0.29), documented family discussions regarding resuscitation status (OR 0.66, CI 0.59-0.75) and at least two nonurgent care record views in the 30 days before death (OR 0.75, CI 0.67-0.84).

Individuals from more deprived areas were less likely to achieve their preferred place of death (OR 0.65, CI 0.54-0.79) and more likely to die in the hospital (OR 1.34, CI 1.11-1.62).

Discussion

Population-level data have identified a change in where people died since the onset of COVID-19 with a sustained increase in home deaths.[11,28] Our large study of routinely collected data from an Electronic Palliative Care Coordination System (Coordinate My Care) provides a unique insight into the end-of-life care preferences and experiences for people in a large urban area who died during the first year of the pandemic.

The data show that during this time most people with serious illnesses, who expressed a preference and had this recorded in the electronic record, wanted to die and be cared for at home/care home. Our analysis identifies that patient-level decision-making and preferences about place of care and death, cardio-pulmonary resuscitation, and ceilings of treatment were associated with where people died, supporting the concept that advance care planning contributes to improved end-of-life outcomes and experiences.[10]

Factors previously identified as being associated with place of death, including performance status and primary diagnosis,[8,22] remained significant during the pandemic. Inequalities in palliative care services for those of lower socio-economic positions are well described.[29] In this study we identified an association between socio-economic position and place of death. Patients who lived in areas of higher socio-economic deprivation, as represented by the IMD, were more likely to die in the hospital and less likely to die in the location of their choice. Additionally, we found that achieving the preferred place of death was associated with other modifiable factors, including the discussion of resuscitation recommendations with family. People whose electronic record was reviewed more frequently before death were more likely to die in their preferred place and less likely to die in hospital, highlighting the relevance of accessible care records.

Given the increased national emphasis on the provision of and engagement with advance care planning,[16] concerns regarding the quality of the process employed have been raised.[14] When considering the quality of end-of-life care, both patient-focused and service-related outcomes must be considered. Our study indicates that, even in these unprecedented circumstances, digital advance care planning communication platforms contribute to end-of-life care which is in keeping with patient preferences. This provides evidence to support the continued use and development of digital communication systems for patients and health services at the end of life.

Table I. Summary of Results.

	Result Cohort				
Outcome	All deaths n=21 962 n (%)	All deaths with place of death recorded n=11 913 (54.4%) n (%)	All deaths with place of death and preferred place of death recorded n=9971 (45.4%) n (%)	Achieving PPD Patients who died in their preferred place of death n=7668 (34.9%) n (%)	Dying in hospital Patients who died in hospital n=2378 (10.8%) n (%)
Patient characteristics					
Gender					
Female	12,090 (55.1)	6487 (54.5)	5469 (54.9)	4314 (56.3)	1159 (48.7)
Male	9872 (45.0)	5426 (45.6)	4502 (45.2)	3354 (43.7)	1219 (51.3)
Age range					
18-39	107 (0.5)	70 (0.6)	57 (0.6)	46 (0.6)	9 (0.4)
40-49	308 (1.4)	207 (1.7)	143 (1.4)	102 (1.3)	54 (2.3)
50-59	925 (4.2)	606 (5.1)	466 (4.7)	346 (4.5)	139 (5.9)
60-69	1944 (8.9)	1206 (10.1)	979 (9.8)	734 (9.6)	227 (9.6)
70-79	3856 (17.6)	2241 (18.8)	1831 (18.4)	1364 (17.8)	515 (21.7)
80+	14,822 (67.5)	7583 (63.7)	6495 (65.1)	5076 (66.2)	1434 (60.3)
Primary diagnosis					
Dementia	5243 (23.9)	2565 (21.5)	2204 (22.1)	1823 (23.8)	403 (17.0)
Cancer	7569 (34.5)	4948 (41.5)	4176 (41.9)	3232 (42.2)	731 (30.7)
Cardiac	1879 (8.6)	898 (7.5)	749 (7.5)	524 (6.8)	284 (11.9)
Respiratory	1456 (6.6)	717 (6.0)	550 (5.5)	384 (5.0)	228 (9.6)
†Other than above	5814 (26.5)	2785 (23.4)	2292 (23.0)	1705 (22.2)	732 (30.8)
Missing	1 (0.0)	2 (0.0)	1 (0.0)		
WHO performance status					
0 -1	838 (3.8)	396 (3.3)	247 (2.5)	139 (1.8)	184 (7.7)
2	2284 (10.4)	1190 (10.0)	836 (8.4)	514 (6.7)	389 (16.4)
3	6320 (28.8)	3354 (28.2)	2690 (27.0)	1863 (24.3)	872 (36.7)
4	12,512 (57.0)	6971 (58.5)	6197 (62.2)	5152 (67.2)	931 (39.2)
Missing	8 (0.0)	2 (0.0)	1 (0.0)		2 (0.1)
IMD quintile					
(Least Deprived) 1	3218 (14.7)	1817 (15.3)	1511 (15.2)	1205 (15.7)	332 (14.0)
2	4148 (18.9)	2278 (19.1)	1960 (19.7)	1549 (20.2)	375 (15.8)
3	4574 (20.8)	2372 (19.9)	1995 (20.0)	1539 (20.1)	479 (20.1)
4	6286 (28.6)	3481 (29.2)	2911 (29.2)	2217 (28.9)	728 (30.6)
(Most Deprived) 5	3210 (14.6)	1681 (14.1)	1359 (13.6)	982 (12.8)	404 (17.0)
Missing	526 (2.4)	284 (2.4)	235 (2.4)	176 (2.3)	60 (2.5)
Record Creation Consent type					
Aged >18 and consented to record creation	13,189 (60.1)	7483 (62.8)	6162 (61.8)	4509 (58.8)	1698 (71.4)
Aged >18 but lacks capacity; BI/LPA decision	8773 (39.9)	4430 (37.2)	3809 (38.2)	3159 (41.2)	680 (28.6)
Lives in care home?					
No	6768 (30.8)	8594 (72.1)	7089 (71.1)	5339 (69.6)	1812 (76.2)

(continued)

Table I. (continued)

			Result Cohort		
Outcome	All deaths n = 21 962 n (%)	All deaths with place of death recorded n = 11 913 (54.4%) n (%)	All deaths with place of death and preferred place of death recorded n = 9971 (45.4%) n (%)	Achieving PPD Patients who died in their preferred place of death n = 7668 (34.9%) n (%)	Dying in hospital Patients who died in hospital n-2378 (10.8%) n (%)
Engagement with ACP					
Yes	15,194 (69.2)	3319 (27.9)	2882 (28.9)	2329 (30.4)	566 (23.8)
Resuscitation status recorded on record					
For CPR	3183 (14.5)	1323 (11.1)	645 (6.5)	306 (4.0)	722 (30.4)
DNACPR	18,779 (85.5)	10,590 (88.9)	9326 (93.5)	7362 (96.0)	1656 (69.6)
***DNACPR discussed with the patient**					
No	7194 (32.8)	3532 (29.7)	2653 (26.6)	2113 (27.6)	820 (34.5)
Yes	14,768 (67.2)	8381 (70.4)	7318 (73.4)	5555 (72.4)	1558 (65.5)
DNACPR discussed with Family					
No	5645 (25.7)	2722 (22.9)	1840 (18.5)	1175 (15.3)	970 (40.8)
Yes	16,317 (74.3)	9191 (77.2)	8131 (81.6)	6493 (84.7)	1408 (59.2)
Ceiling of Treatment					
Full active treatment inc. CPR	2484 (11.3)	1006 (8.4)	488 (4.9)	226 (3.0)	584 (24.6)
Full active treatment but not CPR	1457 (6.6)	674 (5.7)	474 (4.8)	275 (3.6)	267 (11.2)
Treatment of any reversible conditions inc. hospital admission,	5138 (23.4)	2718 (22.8)	2175 (21.8)	1418 (18.5)	764 (32.1)
Treatment of any reversible conditions but only in the home/hospice setting	7655 (34.9)	4499 (37.8)	4156 (41.7)	3424 (44.7)	444 (18.7)
Symptomatic treatment only	4133 (18.8)	2472 (20.8)	2350 (23.6)	2118 (27.6)	154 (6.5)
Other	76 (0.4)	525 (4.4)	317 (3.2)	202 (2.6)	154 (6.5)
Missing	1019 (4.6)	76 (0.4)	11 (0.1)	5 (0.1)	11 (0.5)
Preferred place of care					
Home	12,524 (57.0)	7460 (62.6)	6612 (66.3)	5008 (65.3)	1343 (56.5)
Care home	6366 (29.0)	3103 (26.0)	2918 (29.3)	2417 (31.5)	466 (19.6)
Hospice	197 (0.9)	124 (1.0)	119 (1.2)	79 (1.0)	24 (1.0)
Hospital	741 (3.4)	295 (2.5)	212 (2.1)	116 (1.5)	168 (7.1)
Other	134 (0.6)	62 (0.5)	47 (0.5)	11 (0.1)	20 (0.8)
Not recorded	2000 (9.1)	869 (7.3)	63 (0.6)	37 (0.5)	614 (25.9)
Preferred place of death					
Home	9907 (45.1)	5955 (50.0)	5955 (59.7)	4658 (60.8)	942 (39.6)
Care home	5844 (26.6)	2895 (24.3)	2895 (29.0)	2411 (31.4)	409 (17.2)
Hospice	1180 (5.4)	791 (6.6)	791 (7.9)	464 (6.1)	115 (4.8)
Hospital	454 (2.1)	198 (1.7)	198 (2.0)	124 (1.6)	116 (4.9)
Other	285 (1.3)	132 (1.1)	132 (1.3)	11 (0.1)	39 (1.6)
Not recorded	4292 (19.5)	1942 (16.3)			757 (31.8)
Preferred place of care and preferred place of death align					
No	4332 (19.7)	2231 (18.7)	1090 (10.9)	571 (7.5)	673 (28.3)
Yes	17,630 (80.3)	9682 (81.3)	8881 (89.1)	7097 (92.6)	1705 (71.7)

(continued)

5

Table 1. (continued)

		Result Cohort			
Outcome	All deaths n = 21 962 n (%)	All deaths with place of death recorded n = 11 913 (54.4%) n (%)	All deaths with place of death and preferred place of death recorded n = 9971 (45.4%) n (%)	Achieving PPD Patients who died in their preferred place of death n = 7668 (34.9%) n (%)	Dying in hospital Patients who died in hospital n-2378 (10.8%) n (%)
Actual place of death					
Home	5339 (24.3)	5339 (44.8)	4759 (47.7)	4425 (57.7)	
Care home	3027 (13.8)	3027 (25.4)	2647 (26.6)	2411 (31.4)	
Hospice	1140 (5.2)	1140 (9.6)	923 (9.3)	571 (7.5)	
Hospital	2378 (10.8)	2378 (20.0)	1621 (16.3)	255 (3.3)	
Other	29 (0.1)	29 (0.2)	21 (0.2)	6 (0.1)	
Not recorded	10,049 (45.8)				
Actual place of death matched preferred place of death (where both recorded)					
Yes			7668 (76.9)		263 (11.1)
No			2303 (23.1)		2115 (88.9)
Actual place of death when preferred place of death achieved (Where both recorded)					
Home				4425 (57.7)	
Care home				2411 (31.4)	
Hospice				571 (7.5)	
Hospital				255 (3.3)	
Other				6 (0.1)	
Actual place of death when no preferred place of death recorded		n = 1942			
Home		580 (29.9)			
Care home		380 (19.6)			
Hospice		217 (11.2)			
Hospital		757 (39.0)			
Other		8 (0.4)			
Record use					
Total nonurgent care views in last 30 days					
Median (IQR)	2 (0-5)	3 (0-6)	3 (1-7)	4 (1-7)	4 (1-7)
Range	0-112	0-112	0-112	0-45	0-112
At least 2 nonurgent care views	11,655 (53.1)	7621 (64.0)	7053 (70.7)	5550 (72.4)	1198 (50.4)
Total urgent care views in last 30 days					
Median (IQR)	0 (0-1)	0 (0-1)	0 (0-1)	0 (0-1)	1 (0-2)
Range	0-23	0-22	0-22	0-22	0 -20
Patients with no urgent care record views	13,096 (59.6)	7001 (58.8)	5928 (59.5)	4738 (61.8)	1166 (49.0)
At least 1 urgent care view	8866 (40.4)	4912 (41.2)	4043 (40.6)	2930 (38.2)	1212 (51.0)

Abbreviations: IMD: index of multiple deprivations; COVID-19, coronavirus disease 2019; ACP, advance care planning.
†Other diagnoses include neurological, gastro-intestine, renal, endocrine, haematological, mental health, musculoskeletal, vascular, COVID-19, "Other." *Not included in the model due to collinearity. Variables with significant missing data: Ethnicity, capacity to make and communicate resuscitation decisions, receipt of care, family support,
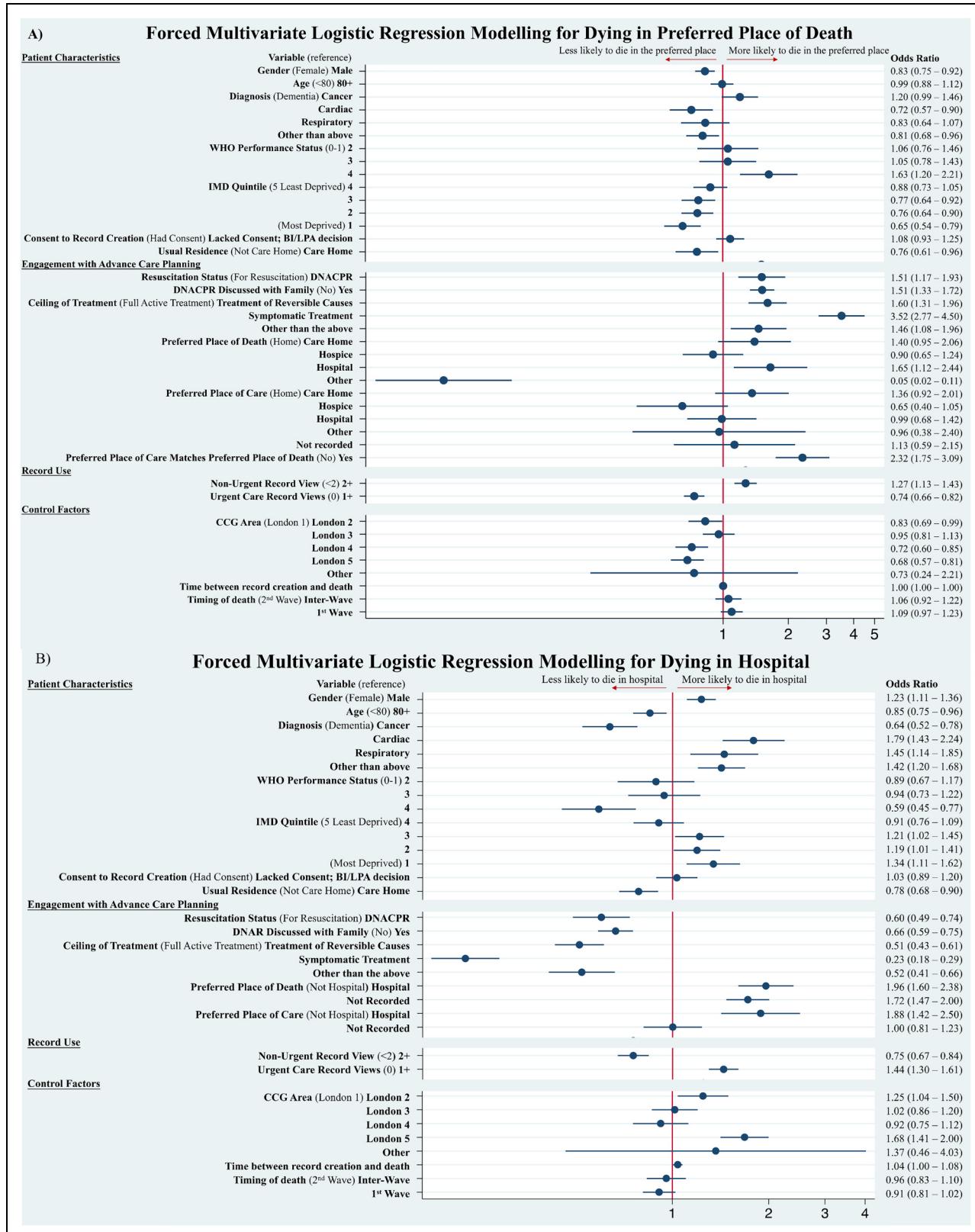
A)

Forced Multivariate Logistic Regression Modelling for Dying in Preferred Place of Death

Less likely to die in the preferred place — More likely to die in the preferred place

Category	Variable (reference)	Odds Ratio
Patient Characteristics		
	Gender (Female) Male	0.83 (0.75 – 0.92)
	Age (<80) 80+	0.99 (0.88 – 1.12)
	Diagnosis (Dementia) Cancer	1.20 (0.99 – 1.46)
	Cardiac	0.72 (0.57 – 0.90)
	Respiratory	0.83 (0.64 – 1.07)
	Other than above	0.81 (0.68 – 0.96)
	WHO Performance Status (0-1) 2	1.06 (0.76 – 1.46)
	3	1.05 (0.78 – 1.43)
	4	1.63 (1.20 – 2.21)
	IMD Quintile (5 Least Deprived) 4	0.88 (0.73 – 1.05)
	3	0.77 (0.64 – 0.92)
	2	0.76 (0.64 – 0.90)
	(Most Deprived) 1	0.65 (0.54 – 0.79)
	Consent to Record Creation (Had Consent) Lacked Consent; BI/LPA decision	1.08 (0.93 – 1.25)
	Usual Residence (Not Care Home) Care Home	0.76 (0.61 – 0.96)
Engagement with Advance Care Planning		
	Resuscitation Status (For Resuscitation) DNACPR	1.51 (1.17 – 1.93)
	DNACPR Discussed with Family (No) Yes	1.51 (1.33 – 1.72)
	Ceiling of Treatment (Full Active Treatment) Treatment of Reversible Causes	1.60 (1.31 – 1.96)
	Symptomatic Treatment	3.52 (2.77 – 4.50)
	Other than the above	1.46 (1.08 – 1.96)
	Preferred Place of Death (Home) Care Home	1.40 (0.95 – 2.06)
	Hospice	0.90 (0.65 – 1.24)
	Hospital	1.65 (1.12 – 2.44)
	Other	0.05 (0.02 – 0.11)
	Preferred Place of Care (Home) Care Home	1.36 (0.92 – 2.01)
	Hospice	0.65 (0.40 – 1.05)
	Hospital	0.99 (0.68 – 1.42)
	Other	0.96 (0.38 – 2.40)
	Not recorded	1.13 (0.59 – 2.15)
	Preferred Place of Care Matches Preferred Place of Death (No) Yes	2.32 (1.75 – 3.09)
Record Use		
	Non-Urgent Record View (<2) 2+	1.27 (1.13 – 1.43)
	Urgent Care Record Views (0) 1+	0.74 (0.66 – 0.82)
Control Factors		
	CCG Area (London 1) London 2	0.83 (0.69 – 0.99)
	London 3	0.95 (0.81 – 1.13)
	London 4	0.72 (0.60 – 0.85)
	London 5	0.68 (0.57 – 0.81)
	Other	0.73 (0.24 – 2.21)
	Time between record creation and death	1.00 (1.00 – 1.00)
	Timing of death (2nd Wave) Inter-Wave	1.06 (0.92 – 1.22)
	1st Wave	1.09 (0.97 – 1.23)

B)

Forced Multivariate Logistic Regression Modelling for Dying in Hospital

Less likely to die in hospital — More likely to die in hospital

Category	Variable (reference)	Odds Ratio
Patient Characteristics		
	Gender (Female) Male	1.23 (1.11 – 1.36)
	Age (<80) 80+	0.85 (0.75 – 0.96)
	Diagnosis (Dementia) Cancer	0.64 (0.52 – 0.78)
	Cardiac	1.79 (1.43 – 2.24)
	Respiratory	1.45 (1.14 – 1.85)
	Other than above	1.42 (1.20 – 1.68)
	WHO Performance Status (0-1) 2	0.89 (0.67 – 1.17)
	3	0.94 (0.73 – 1.22)
	4	0.59 (0.45 – 0.77)
	IMD Quintile (5 Least Deprived) 4	0.91 (0.76 – 1.09)
	3	1.21 (1.02 – 1.45)
	2	1.19 (1.01 – 1.41)
	(Most Deprived) 1	1.34 (1.11 – 1.62)
	Consent to Record Creation (Had Consent) Lacked Consent; BI/LPA decision	1.03 (0.89 – 1.20)
	Usual Residence (Not Care Home) Care Home	0.78 (0.68 – 0.90)
Engagement with Advance Care Planning		
	Resuscitation Status (For Resuscitation) DNACPR	0.60 (0.49 – 0.74)
	DNAR Discussed with Family (No) Yes	0.66 (0.59 – 0.75)
	Ceiling of Treatment (Full Active Treatment) Treatment of Reversible Causes	0.51 (0.43 – 0.61)
	Symptomatic Treatment	0.23 (0.18 – 0.29)
	Other than the above	0.52 (0.41 – 0.66)
	Preferred Place of Death (Not Hospital) Hospital	1.96 (1.60 – 2.38)
	Not Recorded	1.72 (1.47 – 2.00)
	Preferred Place of Care (Not Hospital) Hospital	1.88 (1.42 – 2.50)
	Not Recorded	1.00 (0.81 – 1.23)
Record Use		
	Non-Urgent Record View (<2) 2+	0.75 (0.67 – 0.84)
	Urgent Care Record Views (0) 1+	1.44 (1.30 – 1.61)
Control Factors		
	CCG Area (London 1) London 2	1.25 (1.04 – 1.50)
	London 3	1.02 (0.86 – 1.20)
	London 4	0.92 (0.75 – 1.12)
	London 5	1.68 (1.41 – 2.00)
	Other	1.37 (0.46 – 4.03)
	Time between record creation and death	1.04 (1.00 – 1.08)
	Timing of death (2nd Wave) Inter-Wave	0.96 (0.83 – 1.10)
	1st Wave	0.91 (0.81 – 1.02)

Figure 1. (A) Forest plot of odds ratios from forced Logistic Regression modeling on the determinants of dying in the preferred place of death. (B) Forest plot of odds ratios from forced logistic regression modeling on the determinants of dying in hospital. Full results including *p* values are presented in Appendix III.

Strengths and Limitations

This is the first study to examine the relationship between advance care planning and place of death during the COVID-19 pandemic. We were able to include patient-level information including family involvement in serious decision-making, where evidence of their role is still nascent.[30] Enabling and empowering patients to die where they choose may contribute to improved end-of-life experiences. However, we could not identify from these data whether patient experiences of the care received corresponded with expectations of the patients and their families. Place of death was missing from just under half of the initial cohort, limiting the number of records that we could include in the modeling and introducing the potential for selection bias. Digitally linking the patient-centered data in Coordinate My Care with other routinely collected national datasets would strengthen the reliability of these findings and enable the inclusion of other missing predictor variables such as ethnicity.[8,22] Research from the USA indicates individuals from ethnically diverse and minoritized communities have been disadvantaged in terms of advance care planning.[31-34]

Conclusion

Place of death, and whether it is in keeping with the wishes of the patient, and his/her family, is often considered a quality indicator for end-of-life care.[35] Even in the uncertain setting of the pandemic, we found that advance care planning, including documenting and digitally sharing patient-level decision-making and preferences about place of care and death, cardio-pulmonary resuscitation, and ceilings of treatment were associated with where people died and present an opportunity to modify and enhance end-of-life care experiences and outcomes.

Appendix I

The RECORD statement—checklist of items, extended from the STROBE statement, that should be reported in observational studies using routinely collected health data.

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Title and abstract					
	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found		RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included. RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract. RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract.	Page 1-2 (& Title page)
Introduction					
Background rationale	2	Explain the scientific background and rationale for the investigation being reported			3
Objectives	3	State specific objectives, including any prespecified hypotheses			3-4
Methods					
Study design	4	Present key elements of study design early in the paper			4-5
Setting	5	Describe the setting, locations, and			4-5

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	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
		relevant dates, including periods of recruitment, exposure, follow-up, and data collection			
Participants	6	(a) Cohort study—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up Case-control study—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls Cross-sectional study—Give the eligibility criteria, and the sources and methods of selection of participants (b) Cohort study—For matched studies, give matching criteria and number of exposed and unexposed Case-control study—For matched studies, give matching criteria and the number of controls per case		RECORD 6.1: The methods of study population selection (such as codes or algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided. RECORD 6.2: Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided. RECORD 6.3: If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage.	4-5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.		RECORD 7.1: A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.	4-5
Data sources/ measurement	8	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group			5-4
Bias	9	Describe any efforts to address potential sources of bias			10-11, discussed within limitations
Study size	10	Explain how the study size was arrived at			4-5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why			4-5
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used			4-5

(continued)

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
		to examine subgroups and interactions (c) Explain how missing data were addressed (d) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses			
Data access and cleaning methods	..			RECORD 12.1: Authors should describe the extent to which the investigators had access to the database population used to create the study population. RECORD 12.2: Authors should provide information on the data cleaning methods used in the study.	4-5
Linkage	..			RECORD 12.3: State whether the study included person-level, institutional-level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided.	NA
Results					
Participants	13	(a) Report the numbers of individuals at each stage of the study (eg, numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed) (b) Give reasons for nonparticipation at each stage. (c) Consider use of a flow diagram		RECORD 13.1: Describe in detail the selection of the persons included in the study (ie, study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram.	6
Descriptive data	14	(a) Give characteristics of study participants (*eg*, demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) *Cohort study*—summarize			6-8, 15-15, 25-27

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	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
		follow-up time (*eg*, average and total amount)			
Outcome data	15	*Cohort study*—Report numbers of outcome events or summary measures over time *Case-control study*—Report numbers in each exposure category, or summary measures of exposure *Cross-sectional study*—Report numbers of outcome events or summary measures			6-8, 15-15, 25-27
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period			6-8, 15-15, 25-27
Other analyses	17	Report other analyses done—eg, analyses of subgroups and interactions, and sensitivity analyses			6-8, 15-15, 25-27
Discussion					
Key results	18	Summarize key results with reference to study objectives			9-10
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias		RECORD 19.1: Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported.	10-11
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence			9-11
Generalizability	21	Discuss the generalizability (external validity) of the study results			10-11

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	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Other information					
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based			12
Accessibility of protocol, raw data, and programming code	..			RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	12

*See the work of Benchimol et al.[26]
*Checklist is protected under Creative Commons Attribution (CC BY) license.

Appendix II: Summary of Patients With and Without a Recorded Place of Death

Outcome	All deaths n = 21 962 n, (%)	All deaths with place of death recorded n = 11 913 (54.2%) n, (%)	All deaths without a place of death recorded n = 10 049 (45.8%) n, (%)	Proportional test P value
Patient Characteristics				
Gender				
Female	12,090 (55.1)	6487 (54.5)	5603 (55.8)	.052
Male	9872 (45.0)	5426 (45.6)	4446 (44.2)	.052
Age Range				
18-39	107 (0.5)	70 (0.6)	37 (0.4)	.020
40-49	308 (1.4)	207 (1.7)	101 (1.0)	<.001
50-59	925 (4.2)	606 (5.1)	319 (3.2)	<.001
60-69	1944 (8.9)	1206 (10.1)	738 (7.3)	<.001
70-79	3856 (17.6)	2241 (18.8)	1615 (16.1)	<.001
80+	14,822 (67.5)	7583 (63.7)	7239 (72.0)	<.001
Primary diagnosis				
Dementia	5243 (23.9)	2565 (21.5)	2678 (26.7)	<.001
Cancer	7569 (34.5)	4948 (41.5)	2621 (26.1)	<0.001
Cardiac	1879 (8.6)	898 (7.5)	981 (9.8)	<.001
Respiratory	1456 (6.6)	717 (6.0)	739 (7.4)	<.001
[a]Other than above	5814 (26.5)	2785 (23.4)	3029 (30.1)	.362
Missing	1 (0.0)		1 (0.0)	
WHO performance status				
0-1	838 (3.8)	396 (3.3)	442 (4.4)	.011
2	2284 (10.4)	1190 (10.0)	1094 (10.9)	.030
3	6320 (28.8)	3354 (28.2)	2966 (29.5)	.026
4	12,512 (57.0)	6971 (58.5)	5541 (55.1)	<.001
Missing	8 (0.0)	2 (0.0)		
IMD quintile				
(Least Deprived) 1	3218 (14.7)	1817 (15.3)	1401(13.9)	.006
2	4148 (18.9)	2278 (19.1)	1870 (18.6)	.336
3	4574 (20.8)	2372 (19.9)	2202 (21.9)	<.001
4	6286 (28.6)	3481 (29.2)	2805 (27.9)	.032
(Most deprived) 5	3210 (14.6)	1681 (14.1)	1529 (15.2)	.020
Missing	526 (2.4)	284 (2.4)	242 (2.4)	.885

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Outcome	All deaths n = 21 962 n, (%)	All deaths with place of death recorded n = 11 913 (54.2%) n, (%)	All deaths without a place of death recorded n = 10 049 (45.8%) n, (%)	Proportional test *P* value
Record creation consent type				
Aged >18 and consented to record creation	13,189 (60.1)	7483 (62.8)	5706 (56.8)	<.001
Aged >18 but lacks capacity; BI/ LPA decision	8773 (39.9)	4430 (37.2)	4343 (43.2)	<.001
Lives in Care Home?				
No	6768 (30.8)	8594 (72.1)	3449 (34.3)	<.001
Yes	15,194 (69.2)	3319 (27.9)	6600 (65.7)	<.001
Engagement with ACP				
Resuscitation status recorded on record				
For CPR	3183 (14.5)	1323 (11.1)	1090 (10.9)	.637
DNACPR	18,779 (85.5)	10,590 (88.9)	8959 (89.2)	.637
[b]**DNACPR discussed with patient**				
No	7194 (32.8)	3532 (29.7)	3662 (36.4)	<.001
Yes	14,768 (67.2)	8381 (70.4)	6387 (63.6)	<.001
DNACPR discussed with family				
No	5645 (25.7)	2722 (22.9)	2923 (29.1)	<.001
Yes	16,317 (74.3)	9191 (77.2)	7126 (70.9)	<.001
Ceiling of treatment				
Full sctive treatment inc. CPR	2484 (11.3)	1006 (8.4)	1478 (14.7)	<.001
Full active treatment but not CPR	1457 (6.6)	674 (5.7)	783 (7.8)	<.001
Treatment of any reversible conditions inc. hospital admission,	5138 (23.4)	2718 (22.8)	2420 (24.1)	.028
Treatment of any reversible conditions but only in the home/hospice setting	7655 (34.9)	4499 (37.8)	3156 (31.4)	<.001
Symptomatic treatment only	4133 (18.8)	2472 (20.8)	1661 (16.5)	<.001
Other	76 (0.4)	525 (4.4)	494 (4.9)	.074
Missing	1019 (4.6)	76 (0.4)	57 (0.6)	<.001
Preferred place of care				
Home	12,524 (57.0)	7460 (62.6)	5064 (50.4)	<.001
Care home	6366 (29.0)	3103 (26.0)	3263 (32.5)	<.001
Hospice	197 (0.9)	124 (1.0)	73 (0.7)	.015
Hospital	741 (3.4)	295 (2.5)	446 (4.4)	<.001
Other	134 (0.6)	62 (0.5)	72 (0.7)	.058
Not recorded	2000 (9.1)	869 (7.3)	1131 (11.3)	.387
Preferred place of death				
Home	9907 (45.1)	5955 (50.0)	3952 (39.3)	<.001
Care home	5844 (26.6)	2895 (24.3)	2949 (29.4)	<.001
Hospice	1180 (5.4)	791 (6.6)	389 (3.9)	<.001
Hospital	454 (2.1)	198 (1.7)	256 (2.6)	<.001
Other	285 (1.3)	132 (1.1)	153 (1.5)	.009
Not recoded	4292 (19.5)	1942 (16.3)	2350 (23.4)	<.001
Preferred place of care and preferred place of Death Align				
No	4332 (19.7)	2231 (18.7)	2103 (20.9)	<.001
Yes	17,630 (80.3)	9682 (81.3)	7946 (79.1)	<.001
Record use				
Total non-urgent care views in last 30 days				
Median (IQR)	2 (0-5)	3 (0-6)	1 (0-3)	
Range	0-112	0-112	0-40	

(continued)

Outcome	All deaths n = 21 962 n, (%)	All deaths with place of death recorded n = 11 913 (54.2%) n, (%)	All deaths without a place of death recorded n = 10 049 (45.8%) n, (%)	Proportional test P value
At least 2 nonurgent care views	11,655 (53.1)	7621 (64.0)	4034 (40.2)	<.001
Total urgent care views in last 30 days				
Median (IQR)	0 (0-1)	0 (0-1)	0 (0-1)	
Range	0-23	0-22	0-23	
Patients with no urgent care record views	13,096 (59.6)	7001 (58.8)	6095 (60.7)	<.001
At least 1 urgent care view	8866 (40.4)	4912 (41.2)	3954 (39.4)	<.001

Abbreviations: IMD, index of multiple deprivation; IQR, interquartile range; COVID-19, coronavirus disease 2019; WHO, World Health Organization; IMD, index of multiple deprivation.
[a]Other diagnoses include neurological, gastro-intestine, renal, endocrine, haematological, mental health, musculoskeletal, vascular, COVID-19, "Other."
[b]Variables with significant missing data: ethnicity, capacity to make and communicate resuscitation decisions, receipt of care, family support.

Appendix III: Table of Forced-Multivariate Logistic Regression Models

Forced Multivariate Logistic Regression Modelling for Dying in Preferred Place of Death

Variable (Reference)	Odds Ratio (CI)	P Value
Patient Characteristics		
Age *(<80)* 80+	1.00 (0.88 − 1.12)	0.901
Gender *(Female)* Male	0.83 (0.75 − 0.92)	<0.001
Diagnosis *(Dementia)* Cancer	1.14 (0.96 − 1.36)	0.066
Cardiac	0.69 (0.55 − 0.85)	0.004
Respiratory	0.79 (0.62 − 1.01)	0.158
Other than above	0.78 (0.66 − 0.92)	<0.001
World Health Organisation Performance Status *(0-1)* 2	1.05 (0.76 − 1.45)	0.744
3	1.05 (0.78 − 1.43)	0.731
4	1.65 (1.22 − 2.24)	0.002
Index of Multiple Deprivation Quintile *(5 Least Deprived)* 4	0.88 (0.73 − 1.05)	0.150
3	0.77 (0.65 − 0.92)	0.004
2	0.76 (0.65 − 0.90)	0.002
(Most Deprived) 1	0.65 (0.54 − 0.79)	<0.001
Consent to Record Creation *(Had Consent)* Lacked Consent	1.08 (0.93 − 1.25)	0.298
Resuscitation Status *(For Resuscitation)* DNACPR	1.55 (1.23 − 1.95)	0.001
Usual Residence *(Not Care Home)* Care Home	0.77 (0.61 − 0.96)	0.018
Engagement with Advance Care Planning		
Preferred Place of Death *(Home)* Care Home	1.41 (0.96 − 2.07)	0.091
Hospice	0.90 (0.65 − 1.24)	0.511
Hospital	1.66 (1.12 − 2.45)	0.012
Other	0.05 (0.02 − 0.11)	<0.001
Preferred Place of Care *(Home)* Care Home	1.36 (0.92 − 2.01)	0.125
Hospice	0.65 (0.40 − 1.05)	0.080
Hospital	0.99 (0.68 − 1.43)	0.940
Other	0.97 (0.39 − 2.43)	0.928
Not recorded	1.14 (0.60 − 2.17)	0.715
Ceiling of Treatment *(Full Active Treatment)* Treatment of Reversible Causes	1.61 (1.32 − 1.97)	<0.001
Symptomatic Treatment	3.55 (2.78 − 4.53)	<0.001
Other than the above	1.46 (1.09 − 1.97)	0.013
Preferred Place of Care Aligns with Preferred Place of Death *(No)* Yes	2.33 (1.75 − 3.10)	<0.001
DNAR Discussed with Family *(No)* Yes	1.53 (1.34 − 1.74)	<0.001
Record Use		
Non-Urgent Record View *(<2)* 2+	1.27 (1.13 − 1.43)	<0.001
Urgent Care Record Views *(0)* 1+	0.74 (0.66 − 0.82)	<0.001
Control Factors		
CCG Area *(London 1)* London 2	0.83 (0.69 − 0.99)	0.037
London 3	0.95 (0.81 − 1.13)	0.582

(continued)

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Forced Multivariate Logistic Regression Modelling for Dying in Preferred Place of Death		
London 4	0.72 (0.60 – 0.85)	<0.001
London 5	0.68 (0.57 – 0.81)	<0.001
Other	0.73 (0.24 – 2.21)	0.584
Time between record creation and death	1.00 (1.00 – 1.00)	0.018
Timing of death *(2nd Wave)* Inter-Wave	1.06 (0.92 – 1.22)	0.425
1st Wave	1.09 (0.97 – 1.23)	0.129

Forced Multivariate Logistic Regression Modelling for Dying in Hospital		
Variable (reference)	**Odds Ratio (CI)**	**P Value**
Patient Characteristics		
Gender *(Female)* Male	1.23 (1.11 – 1.36)	0.008
Age *(<80)* 80+	0.85 (0.75 – 0.96)	<0.001
Diagnosis *(Dementia)* Cancer	0.64 (0.52 – 0.78)	<0.001
Cardiac	1.79 (1.43 – 2.24)	<0.001
Respiratory	1.45 (1.14 – 1.85)	0.003
Other than above	1.42 (1.20 – 1.68)	<0.001
World Health Organisation Performance Status *(0-1)* 2	0.89 (0.67 – 1.17)	0.394
3	0.94 (0.73 – 1.22)	0.644
4	0.59 (0.45 – 0.77)	<0.001
Index of Multiple Deprivation Quintile *(5 - Least Deprived)* 4	0.91 (0.76 – 1.09)	0.282
3	1.21 (1.02 – 1.45)	0.031
2	1.19 (1.01 – 1.41)	0.040
(Most Deprived) 1	1.34 (1.11 – 1.62)	0.003
Consent to Record Creation *(Had Consent)* Lacked Consent	1.03 (0.89 – 1.20)	0.688
Usual Residence *(Not Care Home)* Care Home	0.78 (0.68 – 0.90)	0.001
Engagement with Advance Care Planning		
Resuscitation Status *(For Resuscitation)* DNACPR	0.60 (0.49 – 0.74)	<0.001
DNAR Discussed with Family *(No)* Yes	0.66 (0.59 – 0.75)	<0.001
Ceiling of Treatment *(Full Active Treatment)* Treatment of Reversible Causes	0.51 (0.43 – 0.61)	<0.001
Symptomatic Treatment	0.23 (0.18 – 0.29)	<0.001
Other than the above	0.52 (0.41 – 0.66)	<0.001
Preferred Place of Death *(Not Hospital)* Hospital	1.96 (1.60 – 2.38)	<0.001
Not Recorded	1.72 (1.47 – 2.00)	<0.001
Preferred Place of Care *(Not Hospital)* Hospital	1.88 (1.42 – 2.50)	<0.001
Not Recorded	1.00 (0.81 – 1.23)	0.990
Record Use		
Non-Urgent Record View *(<2)* 2+	0.75 (0.67 – 0.84)	<0.001
Urgent Care Record Views *(0)* 1+	1.44 (1.30 – 1.61)	<0.001
Control Factors		
CCG Area *(London 1)* London 2	1.25 (1.04 – 1.50)	0.017
London 3	1.02 (0.86 – 1.20)	0.834
London 4	0.92 (0.75 – 1.12)	0.410
London 5	1.68 (1.41 – 2.00)	<0.001
Other	1.37 (0.46 – 4.03)	0.570
Time between record creation and death	1.04 (1.00 – 1.08)	0.026
Timing of death *(2nd Wave)* Inter-Wave	0.96 (0.83 – 1.10)	0.546
1st Wave	0.91 (0.81 – 1.02)	0.113

Authors' Contributorship

PM, JD, MO, JRo, AB, MP, and JRi designed the study. JD led the PPI work. PM analyzed and interpreted the data with statistical support provided by CB and JD. JD, JRo, AB, MP, KES, MO, JK, and JRi provided support in interpreting the data. PM drafted the manuscript. All authors provided have revised the article critically for clarity and intellectual content provided revisions and have approved this version for submission.

Data Management and Sharing

Anonymized data from this study are stored on the Biomedical Research Informatics Digital Environment, a Trusted Research Environment and informatics platform at The Royal Marsden

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