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COVID-19, deaths at home and end-of-life cancer care

Anastasia Arabadzhyan, Katja Grašič, Peter Sivey *

Centre for Health Economics, University of York, UK

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ABSTRACT

During the COVID-19 pandemic there was a period of high excess deaths from cancer at home as opposed to in hospitals or in care homes. In this paper we aim to explore whether healthcare utilisation trajectories of cancer patients in the final months of life during the COVID-19 pandemic reveal any potential unmet healthcare need. We use English hospital records linked to data on all deaths in and out of hospital which identifies the cause and location of death.

Our analysis shows that during the periods of peak COVID-19 caseload, patients dying of cancer experienced up to 42% less hospital treatment in their final month of life compared to historical controls. We find reductions in end-of-life hospital care for cancer patients dying in hospitals, care homes/hospices and at home, however the effect is amplified by the shift to more patients dying at home. Through the first year of the pandemic in England, we estimate the number of inpatient bed-days for end-of-life cancer patients in their final month reduced by approximately 282,282, or 25%.

For outpatient appointments in the final month of life we find a reduction in face-to-face appointments and an increase in remote appointments which persists through the pandemic year and is not confined only to the periods of peak COVID-19 caseload.

Our results suggest reductions in care provision during the COVID-19 pandemic may have led to unmet need, and future emergency reorganisations of health care systems must ensure consistent care provision for vulnerable groups such as cancer patients.

1. Introduction

Across most healthcare systems, the COVID-19 pandemic has led to large changes in healthcare provision for non-COVID-19 patients. The utilisation of many forms of care fell during the pandemic, including elective and emergency surgery in the UK (Iacobucci, 2020; Dobbs et al., 2021), Canada (Rennert-May et al., 2021) and the US (Birkmeyer et al., 2020; Nourazari et al., 2021). This has been driven by changes in both patients' demand for services as well as hospitals' supply of medical care. On the supply-side, many health systems (including the English National Health Service - NHS[1]) cancelled non-urgent operations and encouraged early discharge of patients. On the demand-side we observe large falls in patient-initiated care, including attendances at hospital emergency departments and general practitioner (GP) surgeries (Burn et al., 2021). This pattern is particularly apparent during the peaks of hospitalisation rates for COVID patients (Iacobucci, 2020).

Concerns were raised at the time (Spicer et al., 2020; Lai et al., 2020) and by later research (Watt et al., 2022) about changes and reductions in care offered to cancer patients during the pandemic. Alongside the drop in the utilisation of care, there was a notable increase in the number of people dying of cancer (Kontopantelis et al., 2021), especially at home compared to in hospitals or care homes. Furthermore, the pattern of excess deaths at home seemed to have persisted through to the period of low COVID-19 deaths in the summer of 2020 (Scobie, 2020) suggesting a more persistent change towards home deaths not just driven by COVID-19 mortality.

These patterns of reduced health care utilisation and excess deaths inform the two hypotheses of this study. Our first hypothesis is that patients who died during the pandemic, would have had access to less end-of-life healthcare than usual, and therefore may have suffered from unmet need. Our second hypothesis is that there may be an increase in unmet need associated with more patients dying *at home* compared to in hospital or in other settings (i.e. care home or hospice).

In this study we aim to identify potential unmet healthcare need for patients in England who died during the COVID-19 pandemic from March 2020 to March 2021. We focus on patients who died of cancer, excluding cases where COVID-19 was mentioned on the death certificate. We use a linked patient-level dataset for all cancer deaths in

* Corresponding author.
E-mail address: peter.sivey@york.ac.uk (P. Sivey).

[1] https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/urgent-next-steps-on-nhs-response-to-covid-19-letter-simon-stevens.pdf

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and out of hospital, which enables us to construct a detailed monthly utilisation history for each patient and analyse data by place of death.

We use Poisson regression models to analyse data on healthcare utilisation for patients in the final month of life from 2016/17 to 2020/21. After accounting for month-of the year effects we separate the impact of the pandemic for each month from April 2020 until March 2021. We conduct the analysis separately for patients who died at home, in hospital and in a care home/hospice setting, to ascertain if place of death during the pandemic was materially associated with changes in the end-of-life care. Next, we study the impact of the pandemic on healthcare utilisation in the last 24 months before death, focusing on utilisation trajectories of patients who died one year after the start of the pandemic (February 2021) and thus spent the whole last year of life in the pandemic period.

Our results show that during the start of the first phase of the COVID-19 pandemic (from April to June 2020), cancer patients in their final month of life suffered a fall in inpatient care equal to approximately 30% to 36% from normal levels conditional on their place of death. This equates to a fall of approximately 1.2 days per month of hospital bed days for patients dying at home, 4.5 bed days per month for patients dying in hospital or 3.7 days for patients dying in a care home/hospice. This fall in care for end-of-life cancer patients had reduced in size and statistical significance by the summer of 2020 when COVID-19 cases were at low levels in the UK, but re-emerged towards the end of 2020 when cases were rising to high levels again. Our results show that the drop in utilisation stems from a decrease in the number of admissions as well as lower length of stay once admitted, although the fall in admissions is confined to the first wave of COVID-19. While we cannot be sure that any reductions in health care utilisation we observe are due to unmet need, the changes that we find during the peak periods of COVID-19 were quickly reversed during the periods of low COVID-19 cases, suggesting they were sub-optimal.

The initial analysis – conducted separately for each place of death – does not account for the shift in the distribution of deaths across settings. Patients dying at home on average utilise substantially less healthcare compared to patients dying in other settings. Increasing the proportion of home deaths thus potentially may increase unmet need. To analyse the overall effect, we also perform the analysis on a pooled sample across all settings. Results suggest that the total drop in inpatient utilisation was as large as 42%, a seven percentage-point larger effect than in the largest decrease in a given month conditional on place of death.

When looking at the results from the models following cohorts of patients dying in February 2021 over their past 24 months of life, and comparing them to cohorts dying prior to the pandemic, the findings largely echo those from the models based solely on the final month of life. Our results also show large changes in outpatient care for cancer patients in their final month of life, with a fall in the number of face-to-face appointments and an increase in remote (telephone/video) appointments, that persisted throughout the first year of the pandemic.

This paper contributes to the literature on the effects of the COVID-19 pandemic on healthcare provision and excess mortality. Our contribution is to link hospital care utilisation for end-of-life cancer patients to place of death over the whole first year of the pandemic. Our research shows the extent to which end-of-life patients suffered a fall in healthcare utilisation, and the dynamics through the different phases of the pandemic.

Studies have quantified the scale of excess deaths through the COVID-19 pandemic, from both COVID-19 and non-respiratory causes including cancer and cardio-vascular disease (CVD). Kontopantelis et al. (2021) confirm the pattern of more excess deaths of patients in private homes and care homes and fewer than normal in hospital. A further study shows that while most of the excess deaths in care homes were for (diagnosed or undiagnosed) COVID-19, the excess deaths for non-COVID-19 (e.g. cancer and CVD) were mainly in private homes (Wu et al., 2021). Studies have shown that for CVD, there were fewer hospital admissions, fewer procedures and more deaths at home compared to pre-pandemic levels (Shoaib et al., 2021; Mohamed et al., 2021). Similarly, cancer patients have experienced disruption in their healthcare pathways. Lai et al. (2020) showed that chemotherapy treatments fell by 40% in the opening months of the pandemic, Watt et al. (2022) showed that urgent cancer referrals and first treatments were down 20% and 16% respectively over the first 10 months of the pandemic compared to expected levels, and Maringe et al. (2020) predicted that the diagnostic delays caused by suspension of screening activities in the first year of the pandemic would lead to a 4.8–16.6% increase in cancer deaths above expected levels.

Studies have also begun to look at the unmet need for healthcare during the pandemic using survey data (Davillas and Jones, 2021; Maddock et al., 2021), showing the degree to which different population groups reported having received lower than usual healthcare levels during the first wave of the pandemic. Research from across several countries shows a reduction in overall healthcare utilisation during the pandemic with falls in hospital admissions averaging 28% across 43 different estimates (Moynihan et al., 2021). Some of these studies confirm a larger decrease in utilisation during the peak months of the pandemic (Mafham et al., 2020). The Online Appendix A gives more details of the COVID-19 pandemic in England.

We also contribute to an understanding of healthcare utilisation in end-of-life care. In this literature there has been a growing evidence of end-of-life care being the primary driver of age-related increase in healthcare expenditures (Zweifel et al., 1999; Howdon and Rice, 2018). End-of-life care for cancer patients is of particular importance, as receiving adequate amount of palliative care can reduce the use of acute and intensive care (De Palma et al., 2018), as well as improve the quality of patients' lives (Zhuang et al., 2018).

2. Data

We use the ONS mortality registration dataset for the period from April 2016 to March 2021 which was the latest data available at the time of analysis. The dataset includes information on all individuals who died in England in that period, including their date and place of death, as well as the main cause of death and relevant co-morbidities. We restrict our analysis to the sample of individuals whose main cause of death was cancer (including neoplasms).[2] To minimise sample selection bias across years, we exclude individuals who either had COVID-19 diagnosis recorded on the death certificate or were hospitalised with COVID-19 prior to death (even if discharged before death). This excludes 9130 cases. In total, our full sample includes 796,811 records, 130,490 of which come from individuals who died during the COVID-19 pandemic (from 15th of March 2020 onwards).

We link the mortality data with the patient level Hospital Episode Statistics (HES) Inpatient and Outpatient datasets for the period from April 2012 to March 2021. This provides us with information on patient's healthcare utilisation prior to death, as well as their socio-demographic characteristics. The data link is based on the unique patient identifier, which enables us to identify all relevant inpatient stays and outpatient attendances for each individual in the 24 months prior to death. Based on the admission, discharge and attendance date we apportion admissions, inpatient bed days, and length-of-stay per admission to the relevant month prior to death assuming each month is 30 days long.

[2] We only include individuals whose primary cause of death is an ICD-10 code from chapter *C* or one of the *D37*-D48** codes from chapter *D*.

2.1. Outcome (utilisation) variables

With our analysis we aim to establish any changes to healthcare utilisation for patients who died during the COVID-19 pandemic. We characterise utilisation using several different measures:

- *Inpatient bed days:* For each individual we calculate the number of days spent as an inpatient in hospital in a given month before death.
- *Number of hospital admissions:* For each individual we establish how many times they were admitted to hospital in a given month before death.
- *Length of stay (LoS) per admission:* For each individual we calculate the number of days spent in hospital in a given month before death, conditional on admission. For a patient who has not been admitted in a given month, this variable will take a missing value. This measure allows us to distinguish whether the changes observed in inpatient bed days were due to reduced probability of admission only (extensive margin), or also because admitted patients saw a change in their LoS (intensive margin).
- *Number of outpatient appointments:* Using HES outpatient dataset, we calculate for each individual the number of outpatient appointments in a given month before death. We further separate appointments that took place face-to-face and remote attendances (including over the phone).

2.2. Control variables

We use explanatory variables in our model to control for patient casemix changes for those who died before and during the pandemic. These include type of cancer (dummy variables for the six most common types and 'other'), sex (male = 1), age (in 5-year brackets), ethnicity, coded in 6 categories[3] (White, Asian excluding Chinese, Chinese, Mixed, Black and other/unknown) and deprivation. The latter is measured using the 2010 income domain of the English Index of Multiple Deprivation (measured in quintiles). We also control for clinical characteristics including binary indicators for 30 Elixhauser conditions observed in the 24 months prior to death.[4]

2.3. Descriptive statistics

Our sample consists of 796,811 death records of cancer patients in England, of which 666,321 are from the pre-pandemic period and 130,490 from the pandemic period. There has been a substantial shift in the distribution of cancer deaths across settings. In the pre-pandemic period, home, hospital and care home deaths accounted for about 30%, 5.6% and 64.4% respectively, whereas during the pandemic the corresponding shares were 44.6%, 3.9% and 51.5%.

Table 1 shows the variation in outcome variables across places of death in the pre-pandemic period: those dying at home have substantially lower inpatient bed days, number of admissions and LoS per admission, but a higher average number of outpatient appointments. During the pandemic, bed days and LoS per admission saw a decrease in all settings, while the number of admissions was slightly higher for hospital deaths. In contrast, the number of outpatient appointments one month before death was higher during the pandemic, driven by an increase in remote consultations. As regards socio-demographic characteristics, a slightly higher proportion of males is observed among home deaths than in other settings. Individuals who died at home tend to be younger on average than those dying in hospitals and in care

Table 1
Descriptive statistics for outcomes and socio-demographic variables.

	A. Pre-pandemic period					
	Home		Hospital		Care home/ hospice	
Outcomes (1 m prior to death)	Mean	SD	Mean	SD	Mean	SD
Inpatient bed days	4.101	6.538	13.541	9.394	10.257	9.906
Number of admissions	0.499	0.902	1.194	0.743	0.918	1.105
LoS per admission	9.061	7.036	13.542	9.394	13.966	9.044
# of outpatient appointments	1.490	4.673	1.216	2.413	1.210	2.784
face-to-face	1.309	4.182	1.134	2.249	1.104	2.542
remote	0.180	0.952	0.082	0.501	0.107	0.652
Control variables						
Proportion male	0.557	0.497	0.531	0.499	0.526	0.499
Age	72.928	11.676	75.227	12.194	73.478	12.715
Deprivation score	0.142	0.107	0.149	0.109	0.143	0.105
Ethnicity						
White	0.834	0.372	0.811	0.392	0.839	0.368
Mixed	0.004	0.065	0.003	0.054	0.003	0.058
Asian (ex. Chinese)	0.019	0.137	0.016	0.126	0.016	0.126
Chinese	0.001	0.037	0.002	0.040	0.002	0.041
Black	0.011	0.103	0.012	0.108	0.014	0.117
Other/Unknown	0.130	0.336	0.157	0.363	0.126	0.332
# Elixhauser conditions	4.277	2.232	4.415	2.064	4.808	2.297
Cancer types						
Bronchus and lungs	0.217	0.412	0.221	0.415	0.192	0.394
Colorectal	0.093	0.290	0.067	0.250	0.076	0.264
Breast	0.062	0.240	0.058	0.234	0.072	0.258
Prostate	0.072	0.260	0.062	0.240	0.073	0.260
Cervical	0.017	0.130	0.016	0.127	0.020	0.140
Skin	0.018	0.134	0.017	0.128	0.021	0.142
Other	0.521	0.500	0.560	0.496	0.548	0.498
Observations	200,341		37,172		428,808	
	B. Pandemic period					
	Home		Hospital		Care home/ hospice	
Outcomes (1 m prior to death)	Mean	SD	Mean	SD	Mean	SD
Inpatient bed days	3.432	5.797	11.325	8.450	8.258	8.867
Number of admissions	0.479	0.894	1.268	0.751	0.879	1.064
LoS per admission	8.265	6.403	11.325	8.450	12.114	8.284
# of outpatient appointments	1.580	4.322	1.347	2.592	1.314	2.840
face-to-face	1.056	3.603	1.002	2.227	0.930	2.398
remote	0.524	1.311	0.345	0.890	0.383	1.000
Control variables						
Proportion male	0.543	0.498	0.527	0.499	0.521	0.500
Age	72.832	11.650	74.480	12.099	73.194	12.673
Deprivation score	0.140	0.106	0.148	0.109	0.141	0.104
Ethnicity						
White	0.813	0.390	0.765	0.424	0.820	0.384
Mixed	0.004	0.064	0.003	0.053	0.004	0.061
Asian (ex. Chinese)	0.021	0.144	0.017	0.130	0.015	0.122
Chinese	0.002	0.040	0.003	0.051	0.002	0.044
Black	0.013	0.112	0.014	0.119	0.014	0.116
Other/Unknown	0.148	0.355	0.198	0.159	0.146	0.353
# Elixhauser conditions	4.535	2.400	4.689	2.146	5.067	2.445
Cancer types						
Bronchus and lungs	0.201	0.401	0.205	0.403	0.180	0.385
Colorectal	0.092	0.289	0.074	0.261	0.079	0.269
Breast	0.064	0.244	0.057	0.231	0.075	0.263
Prostate	0.076	0.264	0.052	0.222	0.070	0.254
Cervical	0.018	0.133	0.017	0.129	0.021	0.145
Skin	0.019	0.137	0.014	0.119	0.022	0.146
Other	0.530	0.499	0.582	0.493	0.553	0.497
Observations	58,614		4,973		66,903	

Notes: The table shows the mean and standard deviation (SD) for the outcome variables: Inpatient bed days, number of inpatient admissions, length of stay per admission, and number of face to face and remote outpatient appointments. It also shows the mean and SD for the explanatory variables used in the model: proportion of male patients, deprivation (based on the IMD income score), ethnicity and the number of Elixhauser conditions. A large share of other/unknown ethnic group is likely to include mostly non-white ethnicity. Note that deprivation and Elixhauser conditions are reported as continuous variables in the table, though they enter the model as categorical variables (see Table 1 in the Online Appendix C for the prevalence of individual Elixhauser conditions).

[3] We use an ethnicity categorisation similar to the one used by the ONS for the official population statistics.

[4] We chose to use Elixhauser conditions as the Elixhauser index was designed specifically to predict acute healthcare utilisation and mortality.

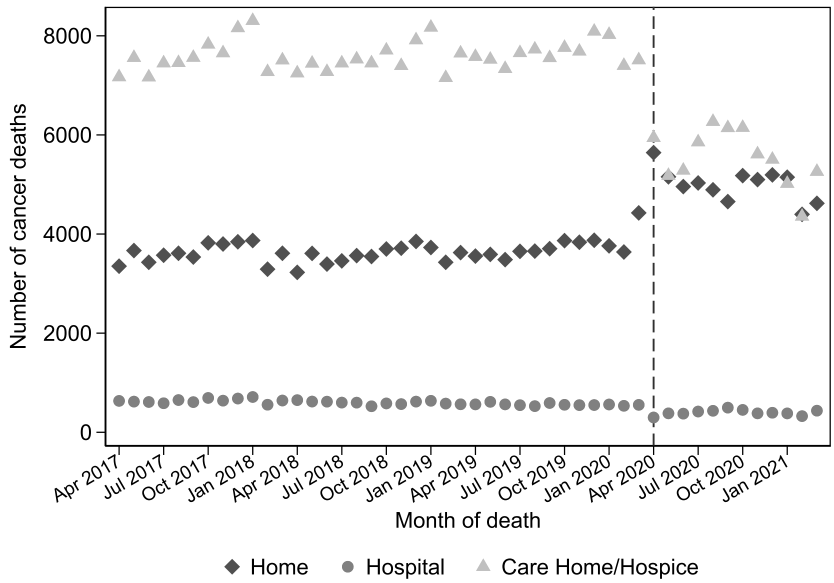


Fig. 1. Monthly cancer deaths at home, in hospitals, and in care homes/hospices.

homes/hospices, and have fewer co-morbidities. The level of deprivation is very similar across different places of deaths and in both periods. Individuals who died during the pandemic were on average slightly younger in all settings, and were more likely to be of a non-white ethnic origin. We also observe that those dying during the pandemic had a higher number of Elixhauser co-morbidities.

3. Descriptive analysis

Fig. 1 depicts the monthly counts of cancer deaths at home, in hospitals, and in other places of death, such as care homes and hospices, from April 2018 to March 2021.[5] The dashed line marks the start of the acute phase of the pandemic in the UK (April 2020).[6] The figure suggests that for hospital cancer deaths, there is a slightly decreasing year-on-year trend, which appears to have accelerated during the pandemic. Care home and hospice cancer deaths have a slight upward trend pre-pandemic, but the number of deaths dropped substantially from a pre-pandemic average of above 7000/month to a post-pandemic average of below 6000/month in April 2020 and remained around that level until March 2021. For deaths at home, there was a slight increasing trend pre-pandemic, with an average of just under 4000/month. This grew substantially in March and April 2020, to an average of nearly 5000/month throughout the rest of the year.

Next, we present the dynamics of the healthcare utilisation measures, starting with the number of admissions and bed days in the final month prior to death.[7] A large majority (>90%) of all end of life inpatient care consists of emergency admissions, with elective care representing only a small fraction of total hospital utilisation. Because of the small numbers of elective admissions, we did not split the hospital activity further into elective and non-elective settings.

Fig. 2 shows that the average number of hospital admissions in the month prior to death was relatively stable for all places of death from April 2018 to April 2020, but rose slightly with the start of the pandemic for those who died in hospitals, and dropped for the other two groups. During the summer months, the average number of hospital admissions returned near to pre-pandemic levels with an unclear trend later in 2020 and early 2021.

The overall mean inpatient bed days in the month prior to death (panel 2(b)) and LoS per admission (panel 2(c)) were also stable before the pandemic, and saw a substantial fall at the onset of the pandemic for patients dying of cancer at home, in hospital or in care home/hospice settings. In summer 2020, bed days and LoS per admission in the month prior to death returned to near-normal levels,[8] before falling again below pre-pandemic levels in autumn and winter (October 2020 to February 2021).

We include descriptive plots and accompanying text for outpatient appointments in the final month of life and inpatient bed days for the final 24 months of life for the February 2020 and February 2021 deaths in Online Appendix B.

Having noted the trends and patterns revealed via graphical investigation, we move to the econometric analysis of healthcare utilisation, which allows us to account for time trends and patient case-mix.

4. Econometric models

We use regression models to quantify the impact of the pandemic on different healthcare utilisation variables for end-of-life patients, whilst controlling for patient-level characteristics, a time trend and seasonal effects.

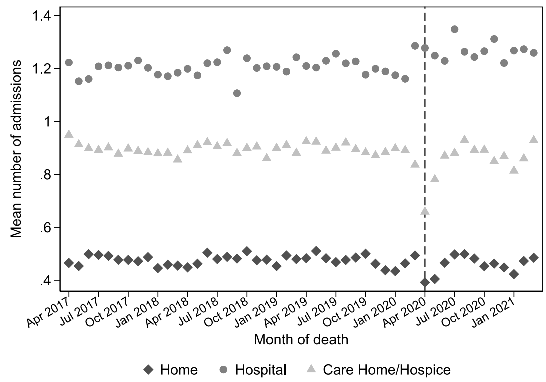
We first estimate the effect of the pandemic on each of our healthcare utilisation measures *in the last month prior to death* for patients who died of cancer, separately in the three settings: home, hospital, and care home/hospice. Since our utilisation variables are count data, we estimate a Poisson regression model, adopting the pseudo-maximum likelihood (PML, sometimes called quasi-maximum likelihood, QML)

[5] We do not observe care home and hospice deaths directly, but assume that people dying not at home or in a hospital died in a care home or a hospice. According to the ONS, for place of death other than home or hospital (‘care home’, ‘hospice’, ‘other communal establishment’, ‘elsewhere’), care homes account for about 73% of deaths, followed by hospices (19%). So, it is reasonable to assume that deaths outside home or hospital are most likely to happen in care homes and hospices.

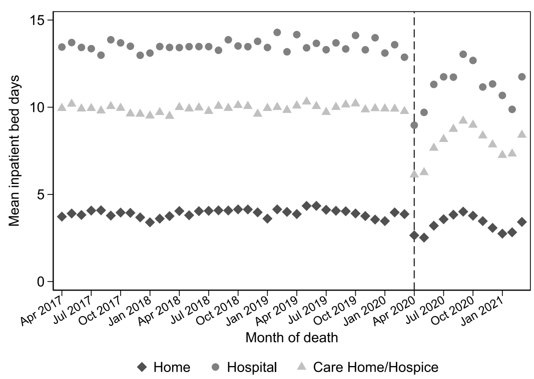
[6] Although the acute phase of the pandemic started in mid-March 2020, we use April in this graphical analysis as the changes in healthcare utilisation are more apparent for deaths in April than in March.

[7] We also conducted the analysis using bed days in the 3 months prior to death, and obtained very similar results.

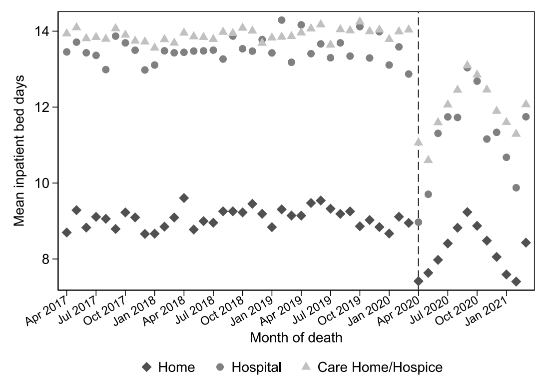
[8] While the fall seems to be the most pronounced for hospital deaths, followed by care home/hospice deaths, in relative terms the fall for home deaths is also substantial.



(a) Number of hospital admissions in the month before death



(b) Inpatient bed days in the month before death



(c) LoS per admission in the month before death

Fig. 2. Average number of admissions (a), total mean inpatient bed days (b), and LoS per admission (c) in the month before death for patients dying of cancer at home, in hospital and in care homes/hospices.

approach such that we only need to assume the correct specification of the conditional mean function to ensure consistent estimates. This approach means that we do not need to adopt all of the traditional assumptions of the Poisson model such as equidispersion, or worry about zero-inflation (Wooldridge, 2010, 1999; Silva and Tenreyro, 2006):

$$E[Y_{it}] = exp(\alpha + \mathbf{X_i'}\boldsymbol{\gamma} + \sum_{h=1}^{H-1} \psi_i^h + \sum_{r=1}^{R-1} \xi_{ih}^r + \delta t + \sum_{m=1}^{11} \omega_t^m + \sum_{m=1}^{12} \theta_t^m P_t) \qquad (1)$$

In this model there is only one observation per patient, where the observed count of Y_{it} (utilisation in the final month of life for patient i who died in month t) is on the left-hand-side. On the right-hand side, α is the intercept, X_i' is the vector of individual-level controls (described in detail in the data section), ψ^h are a set of hospital Trust fixed effects (capturing the hospital Trust of the hospital the patient was most recently treated at), ξ^r are region fixed effects,[9] and δ is a linear monthly time trend. We include a series of dummy variables indicating calendar month-of-the-year ω^m to capture seasonality in end-of-life care, where $m = 1 \dots 11$ (February–December, with January as the reference category which is dropped when the month dummies enter without interactions).

For each of the 12 months from the 15 March 2020, the θ^m coefficients measure the effect of the pandemic for each month over and above the existing month-of-the-year effects and conditional on the linear time trend. The pandemic indicator P_t (=1 for any time point post 15 March 2020, 0 otherwise) selects the θ^m coefficients to be estimated only for the period of the pandemic, for patients whose final month of life was after 15 March 2020. So for a given month in 2020/21, e.g. May 2020, and the corresponding coefficient $\theta^{May2020}$, the relevant counterfactual is May in the period 2017 to 2019, conditional on the linear time trend estimated by δ.

Next, we study whether there is any heterogeneity in the impact of the pandemic on end-of-life cancer healthcare utilisation by socioeconomic status. We estimate a model identical to the one above, apart from instead of a monthly pandemic effect, we interact an indicator of the pandemic P_t (=1 for any time point post 15 March 2020), with local-area deprivation quintiles as follows:

$$E[Y_{it}] = exp(\alpha + \mathbf{X_i'}\boldsymbol{\gamma} + \sum_{h=1}^{H-1} \psi_i^h + \sum_{r=1}^{R-1} \xi_{ih}^r + \delta t + \sum_{m=1}^{11} \omega_t^m + \sum_{d=1}^{5} \Delta^d P_t Dep_i) \quad (2)$$

Here Δ^d is a set of coefficients of the interaction between the pandemic dummy P_t and individual's deprivation quintile Dep_i. These coefficients measure the average effect of the pandemic over the time period of our data for each deprivation quintile.

Finally, we use a different data set up with multiple observations per patient. We focus on a particular cohort of patients who died in February of each year and model the effect of the pandemic on utilisation for each month (up to 24) prior to death.[10] The Poisson

[9] Trusts can have hospitals in different regions, hence the Trust fixed effects and region fixed effects are not collinear.

[10] For those who died in February 2021, the impact of the pandemic on healthcare utilisation is, by construction, 0 for the 13th month before death and beyond.

regression model takes the following form:

$$E[Y_{imt}] = exp(\alpha_i + \delta t + \sum_{m=1}^{23} \lambda^m w_{im} + \sum_{m=1}^{12} \zeta^m P_t w_{im}) \tag{3}$$

Here we define w_{im} as a binary variable equal to 1 if patient i is m months prior to death (in February of 2021, 2020, 2019, 2018, and 2017), and zero otherwise. In contrast to Eqs. (1) and (2), multiple values ($m = 1, \dots, 24$) of the outcome can now be observed for each individual i, while t still stands for the year–month point in time when the healthcare utilisation variable is observed. The coefficients λ_1 to λ_{23} measure the pre-pandemic level of utilisation for each of the 24 months before death (month 24 is dropped as a reference category).[11]

The coefficients ζ_1 to ζ_{12} measure the effect of the pandemic on healthcare utilisation in each month before death for those who died in February 2021, therefore allowing us to observe the impact of the pandemic along the whole final year of the end-of-life healthcare trajectory. In practice, this covers the months of March 2020 to February 2021 for patients who died in February 2021.

Since we have multiple observations per individual, we are able to add individual fixed effects α_i. This allows us to control for time-invariant patient-level heterogeneity, and implies that we estimate the coefficients measuring the effects of the pandemic (the ζs) using within-patient changes in utilisation over time, rather than comparing across patients. Other time-invariant controls (e.g. the hospital Trust fixed effects) would be washed out by the fixed-effects transformation, and therefore, are excluded from this specification.

4.1. Econometric results

4.1.1. Utilisation in the last month prior to death

Table 2 presents the results of the main regression analysis, based on Eq. (1), which estimates the effects of the pandemic on inpatient bed days in the last month before death. The results are presented in terms of the exponents of the coefficients – the incidence rate ratios (IRR) – and portray a large decline in bed days across all three settings (home, hospital and care home/hospice), with the largest average drop observed at the start of the pandemic in April 2020. We estimate a drop of 30% for individuals dying at home, 33.5% for individuals dying in a hospital and 35.6% for individuals dying in a care home/hospice. While the relative drop is similar across settings, this translates into a larger absolute drop for individuals dying in hospital and care home/hospice settings, compared to those dying at home. This is due to the fact that patients dying at home typically spend less time in hospital in the last months compared to those who die in other settings. Using the above coefficients together with the mean inpatient bed days across settings (obtained from Table 1), we can calculate an approximation of the absolute drop in inpatient bed days in April 2020 for patients dying at home, in hospital and in care homes/hospices. Our estimates show a reduction of 1.23 days, 4.54 days and 3.65 days, respectively.[12]

Our specification allows us to document how the effect of the pandemic varied throughout the year. In particular, the fall in inpatient bed days for end-of-life cancer patients had reduced in size by the summer of 2020. For home and hospital deaths, the coefficients for the change in inpatient bed days are not statistically significantly different from zero (i.e. the pre-pandemic levels) during September 2020. This corresponds to a period when COVID-19 cases were at low levels in England. However, with the unfolding of the second wave of the pandemic, when COVID-19 cases and hospitalisations rose to high levels again, bed days for end-of-life cancer patients saw a gradual decrease, falling by up to 25% in February 2021 — smaller in magnitude than at the beginning of the pandemic. The dynamics are similar for hospital and care home/hospice deaths, although those dying in care homes and hospices had a larger fall in bed days in the last month before death throughout the whole pandemic period.

Our results suggest that, conditional on other covariates, age is a relevant predictor only for the care home and hospice deaths sample; for example, patients aged 90 and above spent almost 30% less time in hospitals compared to the 18–24 group. However, we also find that almost all Elixhauser conditions increase length of stay prior to death, with fairly consistent patterns across different settings. The most substantial increases occur if a person has lymphoma, metastatic cancer (though not for hospital deaths), and fluid and electrolyte disorders. Deprivation appears to be relevant for home and care home deaths. We also document an effect of ethnic origin with higher bed days one month prior to death for Black and Asian ethnic groups dying at home and in care homes/hospices.

The drop in the inpatient bed days in the month before death can be due to (i) a drop in the number of admissions to hospital or (ii) a drop in length of stay (LoS) per admission. As can be seen in Table 3(a), we observe a drop in both measures, although the patterns differ across time and settings.

For cancer patients dying at home and in care home/hospice settings the biggest drop in *admissions* is observed for those who died in April 2020 (drop of 16.2% and 23.5%, respectively), with slightly smaller effects in May 2020, and mostly non-significant drops observed in other months. Notably there is little evidence of a fall in the number of admissions in the second wave between December 2020 and February 2021. There was no decrease in the number of admissions for patients who died in hospitals, although this might be due to the changes in patient composition: with more patients dying at home it is likely that the ones who remained in hospitals had additional needs.

Our results for LoS per admission suggest that once admitted, patients were *discharged sooner* during the pandemic compared to the pre-pandemic period, again with the largest effects in the peaks of the two waves of COVID-19. Estimating regression (1) on a sub-sample of individuals who had at least one hospital stay in the last month before death, we find a drop in LoS per admission in all three settings. For individuals dying at home or in a care home/hospice, the decrease is smaller compared to the overall drop in bed days (as shown in Table 2), reflecting the fact that those results capture the decline in the number of admissions as well. For individuals dying in hospital, for which the number of admissions did not change, the results are similar across the two models.

Finally, Table 3(b) shows the impact of the pandemic on the last healthcare utilisation measure: outpatient appointments, separately for the face-to-face and remote modes. The results suggest that for those who died in hospitals and care homes/hospices the average number of face-to-face appointments in the last month before death decreased in the beginning of the pandemic by up to 30.5%. For cancer deaths at home, there was no significant change in face-to-face appointments. Remote appointments saw a substantial increase across all places of death as compared to the pre-pandemic period, and the magnitude of these month-to-month differences was fairly stable throughout the year, substituting for face-to-face consultations and possibly for inpatient care.

4.2. Overall change in end-of-life utilisation

Our results show a substantial drop in inpatient care utilisation during the pandemic across all three places of death: home, hospital and care home/hospice. However, these estimates alone do not fully capture the total drop in utilisation experienced by end-of-life cancer patients during the pandemic. As shown in section 3.3, we observed a large shift in patients' place of death during the pandemic, with a

[11] In this model there is no need to include month-of-the-year dummy variables, they are collinear with the time-to-death dummies as our cohort of patients all died in February. We still include a linear time trend δ which captures aggregate changes in end-of-life healthcare utilisation over time.

[12] We calculate these figures as the pre-pandemic mean bed days multiplied by the IRR coefficient estimated in Table 2.

Table 2
Effects of the COVID-19 pandemic on inpatient bed days in the month prior to death for home, hospital and care home/hospice cancer deaths.

	Home		Hospital		Care home or hospice	
	Estimate	SE	Estimate	SE	Estimate	SE
Pandemic effect						
April 2020	0.700***	0.020	0.665***	0.035	0.644***	0.011
May 2020	0.641***	0.019	0.715***	0.028	0.647***	0.011
June 2020	0.788***	0.022	0.841***	0.033	0.782***	0.012
July 2020	0.896***	0.023	0.880***	0.032	0.847***	0.012
August 2020	0.958	0.025	0.882***	0.033	0.880***	0.012
September 2020	1.035	0.027	0.961	0.031	0.925***	0.013
October 2020	0.951*	0.024	0.953	0.033	0.909***	0.013
November 2020	0.879***	0.023	0.840***	0.035	0.856***	0.013
December 2020	0.837***	0.023	0.853***	0.034	0.815***	0.013
January 2021	0.810***	0.024	0.805***	0.034	0.775***	0.013
February 2021	0.752***	0.023	0.749***	0.033	0.766***	0.013
March 2021	0.974	0.023	0.914**	0.027	0.925***	0.011
Sex						
(reference = female)						
Male	1.023***	0.007	0.973***	0.007	1.050***	0.003
Deprivation						
(reference = least deprived)						
2nd quintile	1.006	0.011	1.012	0.011	1.001	0.004
3rd quintile	1.018	0.010	0.999	0.010	1.017***	0.004
4th quintile	1.035***	0.010	0.984	0.010	1.028***	0.004
Most deprived	1.045***	0.010	0.990	0.011	1.049***	0.005
Age						
(reference = 18–24)						
25–29	0.984	0.096	0.899	0.101	0.916*	0.034
30–34	1.036	0.090	0.897	0.087	0.845***	0.029
35–39	0.958	0.078	0.821*	0.077	0.814***	0.026
40–44	0.940	0.072	0.863	0.073	0.799***	0.024
45–49	0.925	0.068	0.896	0.073	0.800***	0.023
50–54	0.891	0.065	0.850*	0.068	0.787***	0.023
55–59	0.887	0.064	0.854*	0.067	0.787***	0.022
60–64	0.868*	0.062	0.851*	0.067	0.795***	0.023
65–69	0.866*	0.062	0.856*	0.067	0.793***	0.022
70–74	0.861*	0.062	0.849*	0.066	0.792***	0.022
75–79	0.848*	0.061	0.873	0.068	0.777***	0.022
80–84	0.862*	0.062	0.871	0.068	0.758***	0.021
85–89	0.893	0.065	0.858	0.067	0.736***	0.021
90+	0.909	0.066	0.873	0.068	0.701***	0.020
Elixhauser conditions						
(reference = no conditions)						
Congestive Heart Failure	1.088***	0.011	1.001	0.010	1.069***	0.004
Cardiac Arrhythmias	1.147***	0.008	1.050***	0.008	1.112***	0.003
Valvular Disease	1.058***	0.012	1.095***	0.014	1.041***	0.005
Pulmonary Circulation Disorders	1.206***	0.012	1.088***	0.012	1.112***	0.005
Peripheral Vascular Disorders	1.076***	0.011	1.031**	0.012	1.036***	0.004
Hypertension, Uncomplicated	1.040***	0.007	1.020**	0.007	1.025***	0.003
Paralysis	1.167***	0.021	1.170***	0.022	1.090***	0.008
Other Neurological Disorders	1.050***	0.012	1.105***	0.013	1.041***	0.005
Chronic Pulmonary Disease	1.077***	0.008	1.017*	0.008	1.038***	0.003
Diabetes, Uncomplicated	1.017*	0.008	1.002	0.009	1.015***	0.003
Diabetes, Complicated	1.049*	0.020	1.050*	0.023	1.020*	0.008
Hypothyroidism	1.008	0.011	1.041***	0.012	1.017***	0.005
Renal Failure	1.140***	0.010	1.041***	0.010	1.079***	0.004
Liver Disease	1.155***	0.012	0.988	0.011	1.057***	0.005

(*continued on next page*)

substantial increase in the proportion of patients who died at home. Considering that patients who die at home receive less hospital care before death compared to patients who die in other settings, this suggests the overall decrease in care may be even larger than shown in the regression analysis by place of death previously presented in Tables 2 and 3.

Table 4 presents an analysis of the *overall* change in utilisation in the final month of life for the pooled sample of patients who died across all three settings. The results show a similar pattern as the analyses by place of death (Tables 2 and 3), with a large fall in inpatient care utilisation in the final month of life in the periods of peak COVID-19 cases, hospitalisations and deaths (April–May 2020 and December 2020 to February 2021). However the sizes of the estimated effects for the overall change in inpatient utilisation are substantially larger than for the analyses by place of death in Tables 2 and 3. For example, in the first wave, the largest fall in inpatient bed days by place of death is 36%, for patients who died in a care home in April 2020 (see Table 2). In the overall model, the fall in inpatient bed days for those who died in April 2020 is 42% (Table 4). This further reduction in bed days across all settings suggests the changes in location of death with more cancer patients dying at home (see Table 1 and Fig. 1) have amplified the decrease in the use of inpatient healthcare for end-of-life cancer patients during the pandemic.

Furthermore, whereas in the analyses by place of death (Tables 2 and 3) rates of inpatient care utilisation before death almost 'return to normal' in the summer of 2020, in the overall analysis (Table 4), even when COVID-19 hospitalisations are at their lowest in September 2020 we see bed days 11% lower than usual for end-of-life cancer patients. This persistent reduction in bed days in the summer of 2020 reflects the finding in Fig. 1 that the substitution towards more deaths in private

Table 2 (*continued*).

Peptic Ulcer Disease Excluding Bleeding	1.026	0.018	1.065**	0.022	1.051***	0.008
Lymphoma	1.590***	0.022	1.284***	0.018	1.336***	0.007
Metastatic Cancer	1.680***	0.013	1.075***	0.008	1.226***	0.004
Solid Tumor Without Metastasis	1.043***	0.009	1.080***	0.009	1.001	0.004
Rheumatoid Arthritis/Collagen Vascular	1.067***	0.014	1.044**	0.015	1.048***	0.006
Coagulopathy	1.390***	0.017	1.081***	0.015	1.239***	0.006
Obesity	1.112***	0.012	1.069***	0.015	1.062***	0.005
Weight Loss	1.163***	0.011	1.076***	0.011	1.110***	0.005
Fluid and Electrolyte Disorders	1.510***	0.010	1.065***	0.007	1.285***	0.004
Blood Loss Anemia	1.058	0.037	1.119**	0.048	1.070***	0.016
Deficiency Anemia	1.051***	0.010	1.083***	0.012	1.032***	0.004
Alcohol Abuse	0.955**	0.014	0.995	0.015	0.970***	0.006
Drug Abuse	0.883**	0.036	1.035	0.043	0.978	0.015
Psychoses	1.024	0.041	1.190***	0.036	1.034**	0.013
Depression	1.055***	0.011	1.071***	0.013	1.031***	0.004
Hypertension, Complicated	1.098*	0.049	0.933	0.059	1.041*	0.019
Cancer type						
(reference = other)						
Bronchus and lungs	0.900***	0.007	0.868***	0.008	0.921***	0.003
Colorectal	0.697***	0.009	0.904***	0.013	0.809***	0.005
Breast	0.821***	0.011	0.861***	0.014	0.844***	0.005
Prostate	0.753***	0.010	0.947***	0.015	0.869***	0.005
Cervical	0.921***	0.022	1.009	0.026	0.944***	0.010
Skin	0.790***	0.020	0.994	0.026	0.877***	0.009
Ethnicity						
(reference = white)						
Mixed	0.976	0.048	1.061	0.064	0.972	0.023
Asian (exl. Chinese)	1.093***	0.022	1.042	0.026	1.093***	0.010
Chinese	0.952	0.076	0.924	0.080	1.011	0.032
Black	1.189***	0.031	1.044	0.030	1.138***	0.012
Other/unknown	1.000	0.010	0.998	0.009	1.011**	0.004
Constant	2.994***	0.757	13.921***	1.234	8.517***	0.919
Observations	258,955		42,145		495,711	
Trust fixed effects	✓		✓		✓	
Region fixed effects	✓		✓		✓	
Season dummies	✓		✓		✓	
Linear time trend	✓		✓		✓	

Notes: The table presents the IRRs for the coefficients of the main regression. The dependent variable is inpatient bed days in the month before death. The study time span is from April 2015 to March 2021. The pandemic period refers to the period from 15th of March 2020 to 31st of March 2021. Significance levels: * $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$.

homes persisted throughout the summer of 2020, even when COVID-19 cases and hospitalisations were low.

We perform a simple calculation to estimate the proportion of the overall decrease in hospital care that is due solely to the shift in location of death. Taking into account the distribution of patients across the three settings and the mean length of stay in each setting (see Table 1), we can calculate the expected drop in LoS in the month before death if we only observed a change in the distribution across settings. The percentage of patients treated at home, in hospital and in care homes pre-pandemic was 30.07%, 5.58%, and 64.35%, respectively. Post pandemic, this distribution changed to 44.92% dying at home, 3.81% in hospital and 51.27% in care homes/hospices. Using mean LoS for the pre-pandemic period and applying it to both distributions, we observe a 12.76% drop in bed-days (in the month before death) in the post pandemic period that is due to the shift of the place of death distribution. The rest is due to the decrease in utilisation in each of the settings.

We are able to use the figures in Table 4 to calculate an approximate estimate of the reduction in the total number of days of inpatient care for cancer patients in their final year of life due to the pandemic. We use a pre-covid expected utilisation of 8.59 days/month (the average for the period April 2016 to March 2020), and apply the coefficients from the table for the reduction in each month from April 2020 to March 2021.[13] We estimate a reduction of 282,282 bed days for cancer patients in the final month of life due to the pandemic, which is about 25.2% of the expected bed days for cancer patients who died in 2020/21. Online Appendix C presents additional model estimates controlling for time since first cancer diagnosis and analysing regional effects of the pandemic.

4.3. Equity effects

Next, we investigate whether there has been any difference in the effects of the pandemic on healthcare utilisation across individuals depending on their local area deprivation status. To this end, we use an aggregate pandemic dummy variable (for the period 15 March 2020 to 31 March 2021), interacted with the five deprivation quintile indicators. Table 5 reports the coefficients for these interaction terms obtained in each of the place of death sub-samples for our outcome variables. We find evidence of a socio-economic gradient for cancer patients who died at home when analysing inpatient bed days: those living in areas in the most deprived quintile have seen the largest relative drop in bed days for end-of-life cancer care, a 18.5% fall throughout the first year of the pandemic, compared to only a 13.6% fall for patients living in areas with the lowest levels of deprivation. In all three settings the most deprived group is, at the same time, the one that saw the highest relative jump in remote outpatient appointments, at least partly due to the fact that the most deprived group had the lowest level of remote consultations pre-pandemic.

4.4. End-of-life healthcare trajectories

So far our results suggest a substantial drop of inpatient activity in the *last month* before death for cancer patients. However, for patients

[13] We first calculated the average pre-pandemic per-death LoS (8.59 days) and estimated the total pandemic LoS as [monthly pandemic deaths × 8.59 days × sum of the 12 IRRs from the overall regression] = 838,627. If all these people actually received the average pre-pandemic LoS per-person LoS of 8.59 days, that would amount to 8.59 × 130,490 = 1,120,909 days. Therefore, the unmet need measured in LoS 1 m before death was in total 1,120,909–838,627 = 282,282 bed days.

Table 3
Effect of the pandemic on the number of admissions, LoS per admission and outpatient attendances in the month prior to death by place of death.

(a) Number of admissions and LoS per admission

	Number of admissions						LoS if admitted					
	Home		Hospital		Care home/hospice		Home		Hospital		Care home/hospice	
	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE
Main effect												
April 2020	0.838***	0.027	1.035	0.039	0.765***	0.016	0.818***	0.017	0.665***	0.035	0.802***	0.011
May 2020	0.853***	0.026	1.052	0.030	0.881***	0.016	0.829***	0.017	0.715***	0.028	0.765***	0.010
June 2020	0.956	0.028	1.013	0.031	0.958*	0.017	0.856***	0.017	0.841***	0.033	0.836***	0.010
July 2020	1.038	0.030	1.063*	0.032	0.987	0.016	0.929***	0.018	0.880***	0.032	0.877***	0.010
August 2020	1.043	0.031	1.036	0.030	1.023	0.016	0.954*	0.018	0.882***	0.033	0.892***	0.010
September 2020	1.014	0.032	1.016	0.030	0.990	0.015	1.019	0.019	0.961	0.031	0.943***	0.010
October 2020	0.916**	0.027	1.027	0.035	1.003	0.016	0.972	0.018	0.953	0.033	0.923***	0.010
November 2020	0.975	0.030	1.057	0.034	0.952**	0.017	0.927***	0.018	0.840***	0.035	0.898***	0.011
December 2020	0.988	0.030	0.979	0.031	0.985	0.017	0.901***	0.018	0.853***	0.034	0.864***	0.011
January 2021	0.968	0.031	1.051	0.037	0.936***	0.018	0.876***	0.019	0.805***	0.034	0.855***	0.011
February 2021	1.024	0.034	1.070*	0.035	0.964	0.018	0.818***	0.018	0.749***	0.033	0.824***	0.011
March 2021	1.097***	0.029	1.035	0.028	1.018	0.014	0.954**	0.017	0.914**	0.027	0.937***	0.009
Observations	258,955		42,145		495,711		258,955		42,145		495,711	
Patient's characteristics	✓		✓		✓		✓		✓		✓	
Trust fixed effects	✓		✓		✓		✓		✓		✓	
Region fixed effects	✓		✓		✓		✓		✓		✓	
Season dummies	✓		✓		✓		✓		✓		✓	
Linear time trend	✓		✓		✓		✓		✓		✓	

(b) Outpatient appointments by mode of attendance

	Face-to-face outpatient appointments						Remote outpatient appointments					
	Home		Hospital		Care home/hospice		Home		Hospital		Care home/hospice	
	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE
Main effect												
April 2020	1.028	0.057	0.695**	0.085	0.723***	0.027	1.955***	0.113	2.216***	0.461	1.973***	0.112
May 2020	1.043	0.054	0.686***	0.067	0.753***	0.030	2.354***	0.136	2.636***	0.517	2.574***	0.131
June 2020	1.048	0.060	0.718**	0.076	0.878**	0.035	2.557***	0.146	2.920***	0.498	2.821***	0.141
July 2020	1.146*	0.061	0.840*	0.075	0.957	0.035	2.647***	0.147	2.978***	0.500	2.863***	0.148
August 2020	1.029	0.049	0.981	0.117	0.935	0.032	2.212***	0.122	2.798***	0.507	2.625***	0.140
September 2020	0.837***	0.038	0.814*	0.069	0.912**	0.029	2.084***	0.117	2.653***	0.431	2.612***	0.127
October 2020	0.890**	0.036	0.951	0.121	0.958	0.031	2.368***	0.127	2.473***	0.410	2.812***	0.128
November 2020	0.891*	0.040	0.944	0.110	0.895**	0.031	2.402***	0.126	2.590***	0.444	2.827***	0.138
December 2020	0.993	0.046	0.973	0.103	0.952	0.032	2.837***	0.147	3.045***	0.490	2.966***	0.133
January 2021	0.891*	0.049	0.775*	0.088	0.864***	0.033	2.791***	0.148	2.730***	0.485	2.798***	0.139
February 2021	0.867**	0.045	0.951	0.122	0.892**	0.037	2.933***	0.170	3.311***	0.588	3.129***	0.163
March 2021	1.034	0.041	0.949	0.078	0.968	0.029	2.089***	0.104	2.023***	0.338	2.415***	0.108
Observations	258,955		42,145		495,711		258,955		42,145		495,711	
Patient's characteristics	✓		✓		✓		✓		✓		✓	
Trust fixed effects	✓		✓		✓		✓		✓		✓	
Region fixed effects	✓		✓		✓		✓		✓		✓	
Season dummies	✓		✓		✓		✓		✓		✓	
Linear time trend	✓		✓		✓		✓		✓		✓	

Notes: The table presents the IRRs for the coefficients of the main regression. The study time span is from April 2015 to March 2021. The pandemic period refers to the period from 15th of March 2020 to 31st of March 2021. Significance levels: * $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$.

who died later in the pandemic, the trajectory of their end-of life care was affected for several months prior to death.

Table 6 shows the results from estimating Eq. (3), the effect of the pandemic on healthcare utilisation across the 12 months prior to death for patients dying in February 2021, compared to patients who died in the month of February[14] in the preceding years (2015–2020). We use a single-month cohort rather than the entire sample for this analysis, as health care utilisation varies both with time to death, and in 2020/21 with the stage of the COVID-19 pandemic. Focusing on a cohort of patients dying in February 2021, compared to February in previous years allows us to more clearly illustrate the effect of different stages of the first year of the pandemic. We estimate these models as before by place of death, and include individual fixed effects to control for unobserved time-invariant heterogeneity at the patient level.

Our results show patients dying in February 2021 had a large drop in bed days in April and May 2020 (11 and 10 months before their death), with a drop of 52% and 42% respectively for patients dying at home, drop of 78% and 81% for patients dying in a hospital and a drop of 53% and 48% for patients dying in a care home/hospice. For patients dying in hospital, there is no consistent statistically significant fall in bed days or admissions after May 2020. For patients dying at home or in care home/hospice settings, our estimates indicate a persistent drop in healthcare utilisation, measured in bed days and the number of admissions, across all of the months before death (spanning the remainder of 2020 and early 2021). As for the models on utilisation in the final month before death, we see much larger effects during the peaks of the two pandemic waves in spring 2020 and winter 2020/21, and some evidence of a "return to normal" in the summer of 2020. The models also capture a pronounced drop in face-to-face

[14] This month was chosen as the individuals dying in February 2021 have experienced nearly a whole year before death in the pandemic.

Table 4
Overall change in utilisation.

	Inpatient bed days		Number of admissions		Face-to-face appointments		Remote appointments	
	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE
Main effect								
April 2020	0.579***	0.009	0.724***	0.012	0.883***	0.031	2.134***	0.084
May 2020	0.578***	0.009	0.806***	0.012	0.890***	0.031	2.618***	0.100
June 2020	0.709***	0.010	0.886***	0.013	0.943	0.033	2.817***	0.105
July 2020	0.791***	0.010	0.941***	0.013	1.046	0.034	2.872***	0.107
August 2020	0.835***	0.010	0.972*	0.013	0.966	0.027	2.486***	0.094
September 2020	0.890***	0.011	0.951***	0.013	0.878***	0.023	2.431***	0.089
October 2020	0.851***	0.010	0.924***	0.013	0.934**	0.023	2.679***	0.092
November 2020	0.782***	0.010	0.898***	0.013	0.893***	0.024	2.735***	0.096
December 2020	0.736***	0.010	0.907***	0.013	0.988	0.028	3.073***	0.103
January 2021	0.684***	0.010	0.861***	0.014	0.885***	0.029	3.000***	0.107
February 2021	0.675***	0.010	0.905***	0.014	0.889***	0.029	3.235***	0.124
March 2021	0.868***	0.009	0.985	0.012	0.995	0.023	2.345***	0.078
Observations	796,811		796,811		796,811		796,811	
Patient's characteristics	✓		✓		✓		✓	
Trust fixed effects	✓		✓		✓		✓	
Region fixed effects	✓		✓		✓		✓	
Season dummies	✓		✓		✓		✓	
Linear time trend	✓		✓		✓		✓	

Notes: The table presents the IRRs for the coefficients of the main regression. The study time span is from April 2015 to March 2021. The pandemic period refers to the period from 15th of March 2020 to 31st of March 2021. Significance levels: * $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$.

outpatient appointments, in particular for deaths at home and in care homes/hospices — a pattern that has not emerged from the models estimated just on data from the last month prior to death.

5. Discussion

During the COVID-19 pandemic in England, there has been an increase in deaths at home, and a reduction in deaths in other settings. This had led to concerns over unmet need (Davillas and Jones, 2021), which might be especially acute for patients dying at home who would otherwise have been in hospital. In this paper we investigate potential unmet need in patients dying at home from the most common broad cause of death, cancer. In particular, we analyse data on hospital care utilisation for people dying of cancer in the years before and after the onset of the pandemic.

Patients who died of cancer during the pandemic had fewer inpatient bed days and altered outpatient care, marked by a rise in remote consultations, compared to those who died before the pandemic. Patients experienced an initial 43% reduction in inpatient bed days in the final month of life, with an observed reduction of approximately 25% averaged over the first year of the pandemic. This figure is comparable to the findings from Watt et al. (2022) and Lai et al. (2020) who showed a reduction in urgent cancer referrals, first treatments for cancer and chemotherapy treatments. Our results suggest that the decrease in bed days is due to both a decrease in the number of hospital admissions, and a reduction in the average length of stay per admission.

The reduction in hospital admissions during the COVID-19 pandemic is likely multifactorial. Whilst space constraints were not a predominant issue, as many hospitals reported available beds in non-COVID wards (NHS England, 2021a), internal restructuring in response to the pandemic may have played a significant role. Following national guidance issued in March 2020, hospitals introduced operational changes to allocate resources and staff effectively to COVID-19 care, impacting admissions for other health issues.[15] Additionally, a decrease in individuals seeking non-urgent care, driven by fear of virus exposure or misunderstanding of available services, also likely contributed to reduced admissions (Wong et al., 2020). Therefore, the observed reduction in admissions can be attributed to a combination of internal hospital restructuring and changes in patient healthcare-seeking behaviour during the pandemic. Any policy response aiming to address this issue in potential future pandemics will need to consider both aspects.

Our results show that the size of the reduction in inpatient care was associated with the severity of the pandemic, with the largest effect at the peak of the first wave in April 2020, whereas in the late summer of 2020 when COVID-19 cases and hospitalisations were low, the fall in inpatient care compared to normal was smaller, suggesting that the NHS was less badly disrupted during this period. The shift to more deaths in private homes was persistent throughout the whole first year of the pandemic, contributing to the fall in the overall level of hospital bed days, even when COVID-19 cases were low. As the pandemic worsened again in the winter of 2020/21, the volume of inpatient care for end-of-life cancer patients decreased again, however, overall bed days declined by a smaller amount and almost all of the decline was explained by reduction in length of stay.

Our panel data models analyse the final 24 months of cancer patients lives before and after the pandemic: the results support our earlier findings and show how the normal trajectory of end-of-life care (Howdon and Rice, 2018) has been disrupted by the pandemic.

Our results provide some evidence of a socio-economic gradient in the effects, with the largest reduction in inpatient care among end-of-life cancer patients living in the most deprived areas of England. This matches with the pattern of a socioeconomic gradient in excess deaths in England during the pandemic, although not that of excess cancer deaths for cancer specifically, which showed no gradient (Kontopantelis et al., 2021).

There are two main policy implications of this study. First, our results show the potential unintended consequences of policies enacted in response to the COVID-19 pandemic. For future pandemics, or other health emergencies requiring reorganisations in health care services, policies should be designed to maintain care levels where possible for vulnerable groups such as cancer patients. Our results show a large disruption in healthcare for end-of-life cancer patients, that cannot be characterised as a backlog, or as delayed care.

Second, our results emphasise the importance of integration of end-of-life health care across different settings. While it may be desirable for more cancer patients to spend their final weeks at home rather than in hospital or in a care home/hospice, policymakers must ensure that patients continue to have access to appropriate palliative and other end-of-life care.

[15] https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/urgent-next-steps-on-nhs-response-to-covid-19-letter-simon-stevens.pdf

Table 5
Differences in utilisation in the last month before death across five deprivation groups.

(a) Died at home

	Inpatient bed days		Face-to-face appointments		Remote appointments	
	Estimate	SE	Estimate	SE	Estimate	SE
Pandemic effect						
Least deprived	0.864***	0.014	0.938*	0.028	1.987***	0.064
2nd quintile	0.873***	0.020	0.962	0.036	2.280***	0.098
3rd quintile	0.867***	0.016	0.985	0.031	2.553***	0.099
4th quintile	0.860***	0.016	1.023	0.033	2.652***	0.106
Most deprived	0.815***	0.015	1.042	0.033	3.966***	0.189
Observations	258,955		258,955		258,955	
Patient's characteristics	✓		✓		✓	
Trust fixed effects	✓		✓		✓	
Season dummies	✓		✓		✓	
Linear time trend	✓		✓		✓	

(b) Died in hospital

	Inpatient bed days		Face-to-face appointments		Remote appointments	
	Estimate	SE	Estimate	SE	Estimate	SE
Pandemic effect						
Least deprived	0.859***	0.020	0.937	0.058	2.373***	0.247
2nd quintile	0.864***	0.023	0.885	0.069	2.289***	0.288
3rd quintile	0.861***	0.022	0.805***	0.053	2.891***	0.382
4th quintile	0.832***	0.022	0.880	0.071	2.455***	0.302
Least deprived	0.835***	0.021	0.796**	0.062	4.048***	0.515
Observations	42,145		42,145		42,145	
Patient's characteristics	✓		✓		✓	
Trust fixed effects	✓		✓		✓	
Season dummies	✓		✓		✓	
Linear time trend	✓		✓		✓	

(c) Died in care home/hospice

	Inpatient bed days		Face-to-face appointments		Remote appointments	
	Estimate	SE	Estimate	SE	Estimate	SE
Pandemic effect						
Least deprived	0.816***	0.007	0.878***	0.018	2.300***	0.066
2nd quintile	0.840***	0.009	0.922***	0.023	2.678***	0.093
3rd quintile	0.830***	0.008	0.866***	0.020	2.692***	0.095
4th quintile	0.826***	0.009	0.890***	0.022	2.837***	0.104
Most deprived	0.809***	0.008	0.942*	0.024	3.791***	0.143
Observations	495,711		495,711		495,711	
Patient's characteristics	✓		✓		✓	
Trust fixed effects	✓		✓		✓	
Season dummies	✓		✓		✓	
Linear time trend	✓		✓		✓	

Notes: The table presents the IRRs for the coefficients of Eq. (2). The study time span is from April 2015 to March 2021. The pandemic period refers to the period from 15th of March 2020 to 31st of March 2021. Significance levels: * $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$.

Our study does not come without limitations. Firstly, we cannot rule out the potential presence of reverse causality bias within our analysis. This bias could manifest where the delay in receiving the required healthcare services leads to earlier mortality among some cancer patients, thereby affecting our observations related to end-of-life care utilisation. Such early mortality would, in turn, appear to reduce the utilisation rates of end-of-life care services in our findings. We note that the data from 2020 does not indicate a substantial increase in cancer-related mortality, with the rates of death from cancer falling by 1% for males and 2% for females compared to 2019 (NHS Digital, 2020). This suggests that the immediate impact of this bias may be minimal. Additional longitudinal studies are required to fully understand any long-term implications on cancer mortality.

Second, a reduction in hospital care utilisation during the pandemic period may not necessarily imply a larger unmet need during that time. Our outcomes do not capture any end-of-life health or social care provided at home, with the exception of remote outpatient appointments. We know there were efforts by the NHS to make it easier for cancer patients to receive some care at home during the pandemic (NHS England, 2020, 2021b), including more treatments provided in tablet form as a swap for care provided in hospitals. In this case, the shift to home deaths and less hospital care may not lead to unmet need, but to better care provision at home. Whilst we cannot rule out that these initiatives had some mitigating effect on the reduction in hospital care provision, our results show the degree of reduction in hospital care increased in proportion to the peak waves of the pandemic, both in the first wave (March/April 2020) and in the second wave (December 2020 /January 2021), when efforts to provide more care at home were already underway. If home care provision was truly more optimal, we would surely not see the "return to normal" patterns in between the two waves (in the summer of 2020 and the spring of 2021). This temporary drop in care provision during the peaks of the COVID-19 waves, indicates a potential unmet need during these periods.

The third limitation to consider is the risk of COVID-19 itself. Even if there was a reduction in cancer care provided to patients who died at home, this may be outweighed by a reduction in direct risk from COVID-19 infection for these patients. We know that the pandemic was associated with high levels of excess deaths in care homes directly as a result of COVID-19 infection (Morciano et al., 2021; O'Dowd, 2020), so avoiding care homes during this period may still have been rational, even if cancer care suffers by moving a patient out of a care home to a private home.

Finally, due to data constraints our study period ends in March 2021 and does not capture the longer-run effects of the pandemic. However, our time span still covers the majority of time England experienced COVID-19 related restrictions, with these being gradually eased in spring 2021.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Anastasia Arabadzhyan, Katja Grasic and Peter Sivey all report financial support from the National Institute for Health and Care Research.

Data availability

Data can be requested from NHS England.

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Appendix A. Supplementary data

Supplementary material related to this article can be found online at https://doi.org/10.1016/j.ehb.2023.101338.

Table 6
Trajectories of healthcare utilisation in the 12 months before death.

(a) Inpatient activity

	Home				Hospital				Care home/hospice			
	Inpatient bed days		Number of admissions		Inpatient bed days		Number of admissions		Inpatient bed days		Number of admissions	
	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE
Month before death												
1 [February 2021]	0.703***	0.032	0.906*	0.043	1.017	0.236	1.201	0.194	0.805***	0.033	1.021	0.042
2 [January 2021]	0.616***	0.030	0.790***	0.037	0.799	0.212	0.807	0.141	0.656***	0.031	0.838***	0.036
3 [December 2020]	0.800***	0.040	0.892*	0.042	0.924	0.255	0.953	0.192	0.744***	0.037	0.879**	0.038
4 [November 2020]	0.782***	0.041	0.878**	0.041	1.139	0.355	0.92	0.195	0.784***	0.041	0.877**	0.038
5 [October 2020]	0.851**	0.046	0.883**	0.041	1.232	0.401	1.076	0.229	0.846**	0.046	0.887**	0.039
6 [September 2020]	0.864**	0.047	0.873**	0.040	1.127	0.388	0.903	0.214	0.891*	0.049	0.908*	0.042
7 [August 2020]	0.865*	0.050	0.853***	0.039	0.843	0.287	0.874	0.245	0.822***	0.048	0.821***	0.039
8 [July 2020]	0.828**	0.050	0.774***	0.036	0.401**	0.139	0.636	0.160	0.772***	0.046	0.805***	0.039
9 [June 2020]	0.725***	0.046	0.679***	0.032	1.215	0.496	0.672	0.189	0.726***	0.046	0.761***	0.038
10 [May 2020]	0.579***	0.039	0.642***	0.034	0.189***	0.093	0.338*	0.144	0.523***	0.036	0.652***	0.034
11 [April 2020]	0.478***	0.033	0.585***	0.029	0.226**	0.111	0.418	0.201	0.472***	0.034	0.597***	0.034
12 [March 2020]	0.956	0.065	0.833***	0.037	1.037	0.489	1.216	0.635	0.900	0.063	0.835***	0.042
Observations	258,955		258,955		42,145		42,145		495,711		495,711	
Individual fixed effects		✓				✓				✓		
Season dummies		✓				✓				✓		
Linear time trend		✓				✓				✓		

(b) Outpatient activity

	Home				Hospital				Care home/hospice			
	Face-to-face appointments		Remote appointments		Face-to-face appointments		Remote appointments		Face-to-face appointments		Remote appointments	
	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE
Month before death												
1 [February 2021]	0.674***	0.040	2.140***	0.163	1.193	0.203	3.373***	1.122	0.889*	0.041	2.732***	0.197
2 [January 2021]	0.722***	0.031	2.545***	0.184	1.280	0.242	3.405***	1.155	0.837***	0.037	2.759***	0.194
3 [December 2020]	0.732***	0.027	3.010***	0.220	0.929	0.154	3.590***	1.238	0.832***	0.032	3.041***	0.208
4 [November 2020]	0.710***	0.026	3.216***	0.232	0.988	0.161	4.056***	1.455	0.811***	0.032	3.151***	0.218
5 [October 2020]	0.714***	0.026	2.971***	0.217	0.942	0.157	3.229**	1.177	0.744***	0.028	3.107***	0.216
6 [September 2020]	0.664***	0.023	3.251***	0.237	0.983	0.197	3.487***	1.301	0.724***	0.027	3.253***	0.234
7 [August 2020]	0.648***	0.024	3.519***	0.263	0.609**	0.106	4.890***	1.722	0.692***	0.025	3.583***	0.256
8 [July 2020]	0.608***	0.024	3.398***	0.248	0.558**	0.119	4.199***	1.360	0.686***	0.029	3.729***	0.264
9 [June 2020]	0.534***	0.021	3.573***	0.268	0.423***	0.098	2.590**	0.911	0.638***	0.030	3.754***	0.270
10 [May 2020]	0.507***	0.022	3.290***	0.249	0.513**	0.127	2.364*	0.861	0.548***	0.027	3.618***	0.265
11 [April 2020]	0.531***	0.025	2.703***	0.210	0.549	0.223	2.475*	0.962	0.579***	0.026	3.035***	0.222
12 [March 2020]	0.854***	0.031	1.376***	0.131	0.631*	0.120	1.608	0.723	0.892*	0.040	1.441***	0.142
Observations	258,955		258,955		42,145		42,145		495,711		495,711	
Individual fixed effects		✓				✓				✓		
Season dummies		✓				✓				✓		
Linear time trend		✓				✓				✓		

Notes: The table presents the IRRs for the coefficients of Eq. (3). Significance levels: * $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$.

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