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Health and social care costs at the end of life: a matched analysis of linked patient records in East London

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Keypoints:	The end of life period is associated with high hospital care costs, but less is known about costs in other care settings., We examined cost patterns at the end of life across different care settings in an East London locality., Health and care costs were £7450 higher for patients in their final year of life compared to those not in their final year., Most costs at the end of life related to unplanned hospital care, where costs were more highly concentrated in the final month, As age of death increases, the proportion of care costs relating to social care relative to healthcare increases.

Abstract

Abstract word limit: 250
Currently: 247

Background: Care in the final year of life accounts for 10% of inpatient hospital costs in England. However, there has been little analysis of costs in other care settings. We investigated the publicly funded costs associated with the end of life across different health and social care settings.

Method: We performed cross-sectional analysis of linked electronic health records of residents aged over 50 in a locality in East London, England, between 2011 and 2017. Those who died during the study period were matched to survivors on age group, sex, deprivation, number of long term conditions and time period. Mean costs were calculated by care setting, age, and months to death.

Results: Across 8720 matched patients, the final year of life was associated with £7450 (95%CI £7086 - £7842, p<0.001) of additional health and care costs, 57% of which related to unplanned hospital care. While costs increased sharply over the final few months of life in emergency and inpatient hospital care, in non-acute settings costs were less concentrated in this period. Patients who died at older ages had higher social care costs and lower healthcare costs than younger patients in their final year of life.

Conclusions: The large proportion of costs relating to unplanned hospital care suggests that end-of-life planning could direct care towards more appropriate settings and lead to system efficiencies. Death at older ages results in an increasing proportion of care costs relating to social care than to healthcare, which has implications for an aging society.

Key Points (3-5)

- The end of life period is associated with high hospital care costs, but less is known about costs in other care settings.
- We examined cost patterns at the end of life across different care settings in an East London locality.
- Health and care costs were £7450 higher for patients in their final year of life compared to those not in their final year.
- Most costs at the end of life related to unplanned hospital care, where costs were more highly concentrated in the final months
- As age of death increases, the proportion of care costs relating to social care relative to healthcare increases.

Keywords:

end-of-life, ageing, dying, costs, expenditure

Current word count: 2523

Background

Controlling public expenditure on healthcare related to population ageing and growing health needs is one of the most pressing health policy objectives in England and other high-income countries. Per capita health spending rises with age, with annual costs of £2,300 per person at age 60 and £10,000 at 90 [1]. However, this hides the underlying drivers of healthcare expenditure. The 'red herring' hypothesis, first proposed by Zweifel et al [2], states that it is proximity to death, rather than age per se, that drives healthcare expenditure, and age only appears to explain expenditure because elderly individuals are more likely to be in the period approaching death. The large increase in costs during the end of life period has been confirmed across multiple studies and settings [3,4].

In England, inpatient hospital care in the final year of life has been estimated as £2.5bn, or 10.4% of total expenditure in this setting [5]. Other studies have also found high costs associated with the end of life period [6–9], but are usually limited to hospital settings and exclude community care and social care. Social care refers to support for the activities of daily living (for example, via home visits or residency in a care home), which people are more likely to require as they age. Internationally, studies have found that long term social care expenditures are more greatly influenced by age than proximity to death, unlike hospital expenditure [10–15]. There is little comparable literature in England because healthcare and mortality data has historically not been linked to social care data. Analysis using linked data found that the time-to-death effect applied more strongly for hospital costs than social care costs [17,18].

Unlike healthcare, which is free at the point of use via the National Health Service (NHS), social care is means-tested in England. State funding is only available to those with the highest need and the lowest means [18], with different funding streams and care providers to those found in the NHS. Understanding end-of-life costs across these settings is crucial as the health system attempts to reduce the costs associated with unplanned hospital care by increasing care integration between settings [19]. We therefore investigated the system-wide costs associated with the end of life period, and explored patterns in end of life costs by care setting, age, and time-to-death.

Methods

Setting and population

Barking and Dagenham is a densely populated urban locality in East London, England, with 210,700 residents. The area has a younger average age, more ethnic diversity and high social disadvantage compared to the rest of the country [20]. The study population was defined as individuals aged 50 years and above who lived in Barking and Dagenham between 1st April 2011 and 31st March 2017 and were registered with a GP practice in the locality. We restricted the study to this age group because in younger age groups deaths are more likely to relate to unnatural causes, such as accidents and suicide. This resulted in a study population of 73,736 individuals, of which 5,644 had died over the study period.

Data sources

The source was a novel patient-level linked dataset including events from local government services, health providers and health commissioners in the area. The dataset includes patient demographics, location of residence, mortality information and service utilization across different settings, which are defined in Appendix 1a. Costs were assigned to each unit of activity, using different methods by setting. Primary care costs were estimated from the 2016/17 Personal Social Services Research Unit manual of reference costs [21], with £38 per general practitioner visit and £10.50 for visiting another healthcare professional. Average costs per prescription by primary care practice were applied to each prescription. Secondary care unit costs were taken from the NHS National Reference Costs [22], which are used for calculating payments from commissioners to hospitals in the NHS. Local-government-funded social care costs were obtained from data that lists the weekly billed cost for each care package provided (and therefore allowed for weekly updates to that value if package revisions were made). All costs in the study period were inflated to 2016/17 prices using the Hospital and Community Health Services inflation index [21].

Confounders were variables that we expected to be associated with mortality risk and independently predict healthcare expenditure. We extracted sex, age (in five-year categories), deprivation and morbidity [23]. Local deprivation quintiles were calculated from the 2015 English Index of Multiple Deprivation scores for each patient's neighborhood of residence [24]. Morbidity was taken as the count of up to sixteen diagnosed long term conditions from primary care records [Appendix 1b], with those with five or more grouped.

The dataset included the month but not the day of death. Where care episodes occurred in the month of death, we used the date of the last recorded care episode as the date of death. Where no care episode occurred in the month of death, we used the first day of the month.

Matching

People in their final year of life ('decedents') differ in many respects to those not in their final year of life ('survivors'), with the decedents being older and having a greater degree of morbidity. We matched decedents to survivors using a two-stage process, described in more detail in Appendix 2a. First, we identified all potential matches where decedents and survivors had the same sex, age group, deprivation quintile, number of long term

conditions, and where the survivor was known to be resident in the locality during the decedent's final year of life. Second, we matched survivors and decedents whereby participants with the fewest matches were assigned first in order to maximise the number of total unique matches. The matching algorithm is available here: https://osf.io/jpf2z/. No patients were included more than once. Decedents who could not be matched were excluded. Matched pairs from the final year of the study period were also excluded where the matched survivor was found to have died in the subsequent twelve months (1st April 2017 to 31st March 2018), to prevent misclassification. These exclusions are depicted as a flow diagram in Appendix 2b. By comparing the same time periods of activity between matched pairs, we controlled for potential period effects over the six-years, seasonal effects (such as higher costs in winter months), and changes in prices that were not already accounted for by the overall inflation index.

Analysis

We calculated the mean difference in costs in the final year of life by setting for decedents and survivors, with bootstrapped confidence intervals for paired differences and significance testing via the Wilcoxon signed-rank test. We also disaggregated mean annual costs by age group, and calculated mean monthly costs over the final twelve months before the date of death (or for survivors, the date of the death of their matched decedent). To help visualise patterns, we added lines to scatterplots using locally weighted scatterplot smoothing. In a sensitivity analysis, we examined the effect of including unmatched decedents on health and care costs. All data processing, matching and analyses were conducted using R version 3.5.1.

Ethics

The dataset is not publicly available. It is hosted in the Barking and Dagenham, Havering and Redbridge NHS Accredited Data Safe Haven and contains routinely collected, retrospective, pseudonymised data. It was created for research purposes with ongoing governance and oversight provided by the Barking and Dagenham, Havering and Redbridge Information Governance Steering Committee. This study meets national guidelines set out by the Research Ethics Service for the National Health Service in England. No furthers ethics approval was required (http://www.hra-decisiontools.org.uk/ethics/resultN2.html).

Results

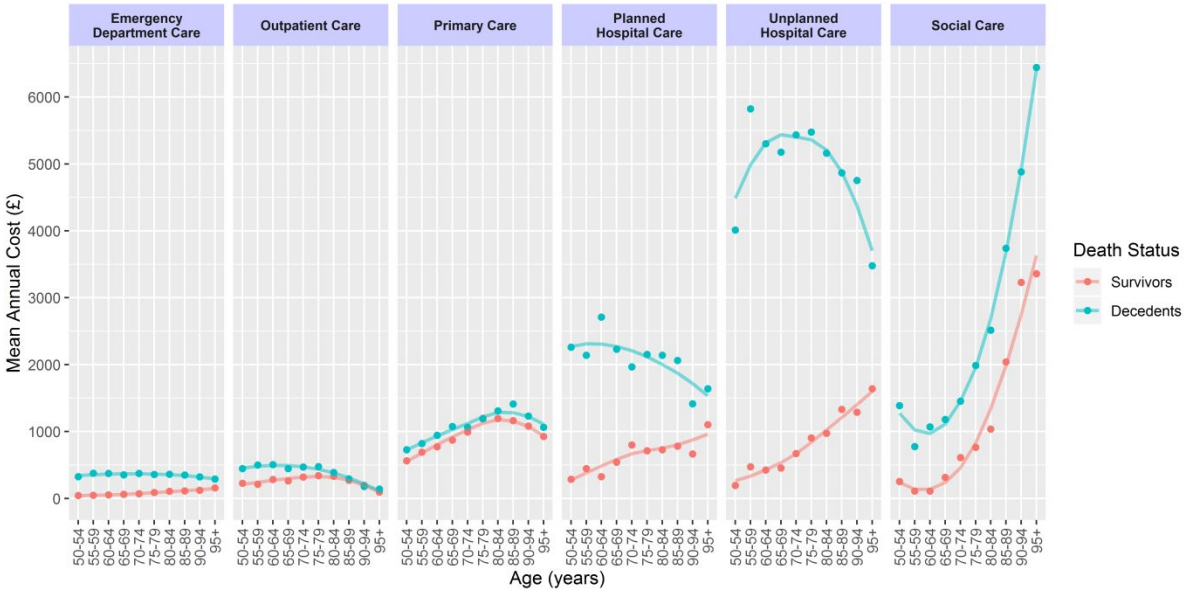
Table 1: Mean annual costs in the final year of life by care setting (GBP, 2016/17 prices)

Care setting	Mean annual cost - survivors	Mean annual cost - decedents	Difference (95% CI)	p-value	% of total cost associated with the end of life
Unplanned Hospital Care	£891	£5,109	£4,218 (4017 – 4434)	p < 0.001	56.6%
Planned Hospital Care	£667	£2,081	£1,414 (1277 – 1558)	p < 0.001	19.0%
Social Care	£1,171	£2,483	£1,312 (1092 – 1546)	p < 0.001	17.6%
Emergency Department Care	£90	£354	£264 (252 – 277)	p < 0.001	3.5%
Primary Care	£1,036	£1,170	£134 (94 – 175)	p < 0.001	1.8%
Outpatient Care	£282	£390	£108 (87 – 129)	p < 0.001	1.5%
Total	£4,136	£11,586	£7,450 (7086 – 7842)	p < 0.001	100.0%

Main results

4360 matched pairs of survivors and decedents (n = 8720) were analysed, following exclusion of 21% of decedents who could not be matched and a further 1.8% decedents where the matched survivor was found to have died in the year following the study period [Appendix 2b]. Comparing paired decedents and survivors, the final year of life was associated on average with an additional cost of £7450 (95%CI £7086 - £7842, p<0.001) [Table 1]. Additional costs at the end of life were found across all care settings, but unplanned hospital care was the largest contributor, accounting for £4218 (57%) of the overall increase in costs. Large differences in costs were also seen for planned hospital care (£1414) and social care (£1312) with smaller differences seen for outpatient care (£108), primary care (£134) and emergency department care (£264). Sensitivity analysis using all decedents (n = 5644), including all those which were excluded, resulted in similar baseline characteristics and returned similar mean costs to the main analysis [Appendix 3].

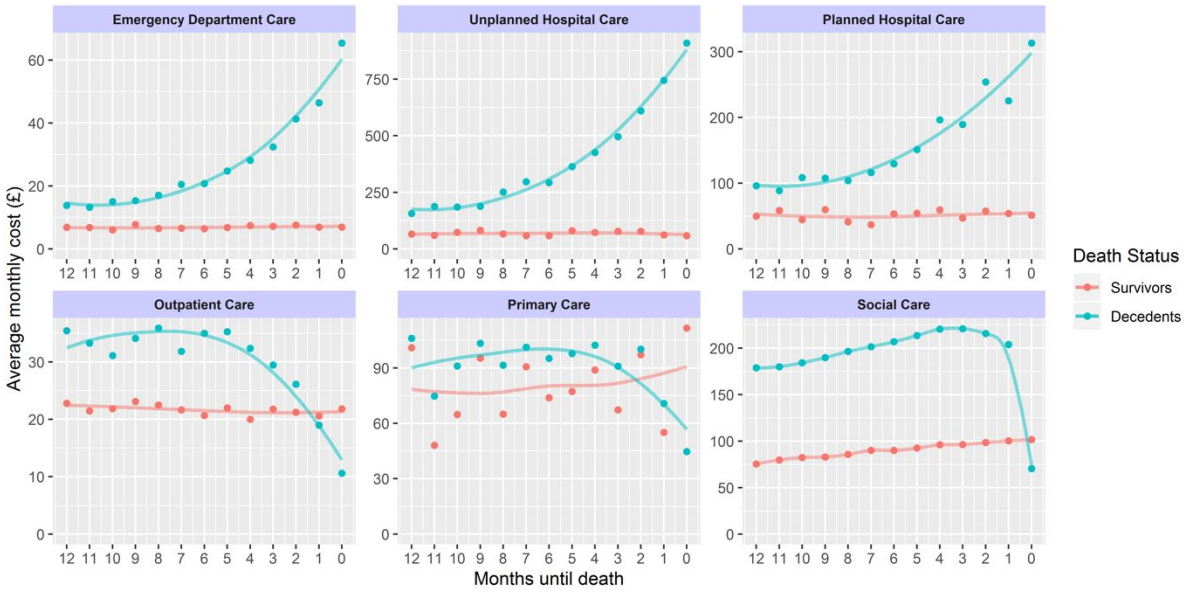
Figure 1: Health and social care costs by death status and age. *A table with the numerical values of the data represented in Figure 1 is provided in Appendix 4.*



Annual costs by age

Health and care costs were higher in decedents than survivors across all settings and age groups, but the age-related patterns in costs and end-of-life care costs differed by setting [Figure 1]. In decedents, costs decreased across most healthcare settings as age increased beyond age 75, particularly for unplanned and planned hospital care, and outpatient care. In survivors, healthcare costs increased with age for emergency department care, and unplanned and planned hospital care, while decreasing for outpatient care and primary care beyond age 75 years and 85 years respectively. Social care costs increased dramatically with age in both decedents and survivors.

Figure 2: Health and social care costs for decedents and survivors by time-to-death (for decedents) and matched time period (for survivors). *A table with the numerical values of the data represented in Figure 2 is provided in Appendix 4.*



Monthly costs by time-to-death

The change in monthly costs during the final year of life also varied by care setting [Figure 2]. In acute settings (emergency department care, planned and unplanned hospital care), monthly costs in the month of death were roughly three times higher than costs twelve months before death, with a sharp increase over the last few months. In non-acute settings (outpatient care, primary care and social care) costs in the final year of life were still higher overall than for survivors, but with a different pattern from month to month, with costs decreasing over the final few months. There was a particularly steep decline in social care costs over the last month of life.

358 words

Discussion

Main findings

In the over 50 years population of a locality in East London, health and care costs were £7,450 higher for patients in their final year of life (£11,586) compared to those not in their final year (£4,136). Unplanned hospital care accounted for the majority of this difference. Patients in their final year of life also had substantially higher costs relating to planned hospital admissions and social care. As age of death increased, healthcare costs in the final year of life decreased, while social care costs continued to increase as for survivors. Monthly costs by time-to-death varied by setting: while costs in acute settings rose steeply during the last few months, costs in non-acute settings were less concentrated over this period.

Comparison with other literature

The only other studies based in England to consider both health and social care costs together arrived at mean costs per person of £10,130 [16] and £9,437 [17] in the final year of life. These are similar figures to ours (£11,586) after accounting for inflation, although these older studies did not include primary care costs. UK-based studies that exclusively consider healthcare expenditure show that costs increase with age among survivors and decrease with age among decedents [5,9,26]. Our analysis reconfirmed these findings for healthcare costs, but additionally found that social care costs, by contrast, increase with age among both survivors and decedents. This is similar to studies from other countries which have found that social care (or equivalent) costs are more age-dependent than hospital costs once accounting for time-to-death [11–15].

Strengths and limitations

A strength of our analysis is that we matched survivors to decedents according to several known confounders, meaning that the cost difference is more likely to be related to the end of life. We also included time period as a matching criterion, which improved on existing analyses by controlling for period effects and seasonality. While 22.8% of all decedents were excluded, sensitivity analysis with all decedents arrived at similar mean costs [Appendix 3].

It is important to note that the social care costs in our study relate only to state-funded care, and we can make no inferences about privately-funded care. 44% of care home placements are self-funded in England [26], although this figure is likely to be lower in Barking and Dagenham due to higher levels of deprivation. Data were also not available for mental health services and community care, which would have provided a more complete picture of system-wide costs. The Barking and Dagenham population is younger, more ethnically diverse and more deprived than the England average [20], which may limit generalization of our results. Finally, there may be residual confounding after matching survivors and decedents. In particular, we matched on the number of long-term conditions, but the groups may differ in terms of the type, severity or combination of conditions, and definitions of multimorbidity continue to evolve in the literature. We also did not analyze place of death which may be an important determinant of costs in the final month.

Policy implications

Understanding care use by setting over the final twelve months could be used to better align care in this period to patient wishes. Most patients prefer to die in their usual place of residence [27], yet in our study, there was a steep rise in emergency and unplanned hospital costs in the final few months of life. Social care costs on the other hand, reduced suddenly in the final month, likely because patients were being admitted to hospital. Better end-of-life planning might reduce this cost-shifting by allowing recipients of social care to die at their usual place of residence, preventing the need for acute hospital admissions, as has been demonstrated in some studies [28]. Such planning might also reduce planned hospital costs, which increased sharply in the final months, potentially reflecting unwarranted elective investigations and procedures on patients for whom end-of-life planning may have been more appropriate. There is some economic evidence that end-of-life planning leads to costs savings, at least for some patients, such as those with dementia or living in care homes [29].

The large costs associated with unplanned hospital admissions at the end-of-life are important in the context of current UK policy to introduce shared planning and budgets across health and care settings [30]. In our study, costs associated with care in the final year of life accounted for around 18% of the overall health and social care expenditure in the over-50 age group (based on the average costs in our results multiplied by the size of the population), highlighting the importance of the end-of-life period to health system planning. Our findings also suggest that an ageing society is likely to lead to a relative shift in care demands at the end of life towards social care, which is important given the current scarcity of funding for social care in England [18].

Conclusions

We demonstrated how costs of care at the end of life in England break down across settings, including social care. The final year of life is associated with high health and care costs, a majority of which relate to unplanned hospital care, and in those dying at older ages, social care costs become more significant. Understanding patterns of care use at the end of life across different settings may be key to understanding interventions designed to keep patients out of hospital in their final months, to the benefit of patients, their families and the efficiency of the system.

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Declarations

The authors declare no conflicts of interest in this work.

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Appendix

APPENDIX 1:

1a: Care Setting Definitions

Care Setting	Definition
Unplanned Hospital Care	Unscheduled (non-elective) care following inpatient admission, funded via the NHS
Planned Hospital Care	Scheduled (elective) procedures, investigations and care funded via the NHS
Social Care	Local government funded care to support activities of daily living, either via home visits or residency in care homes
Emergency Department Care	All types of accident and emergency (A&E) attendances funded via the NHS
Primary Care	NHS-funded care delivered in general practice settings, by both general practitioners (family doctors) and other healthcare professionals, including prescription costs
Outpatient Care	Specialist outpatient attendances funded via the NHS

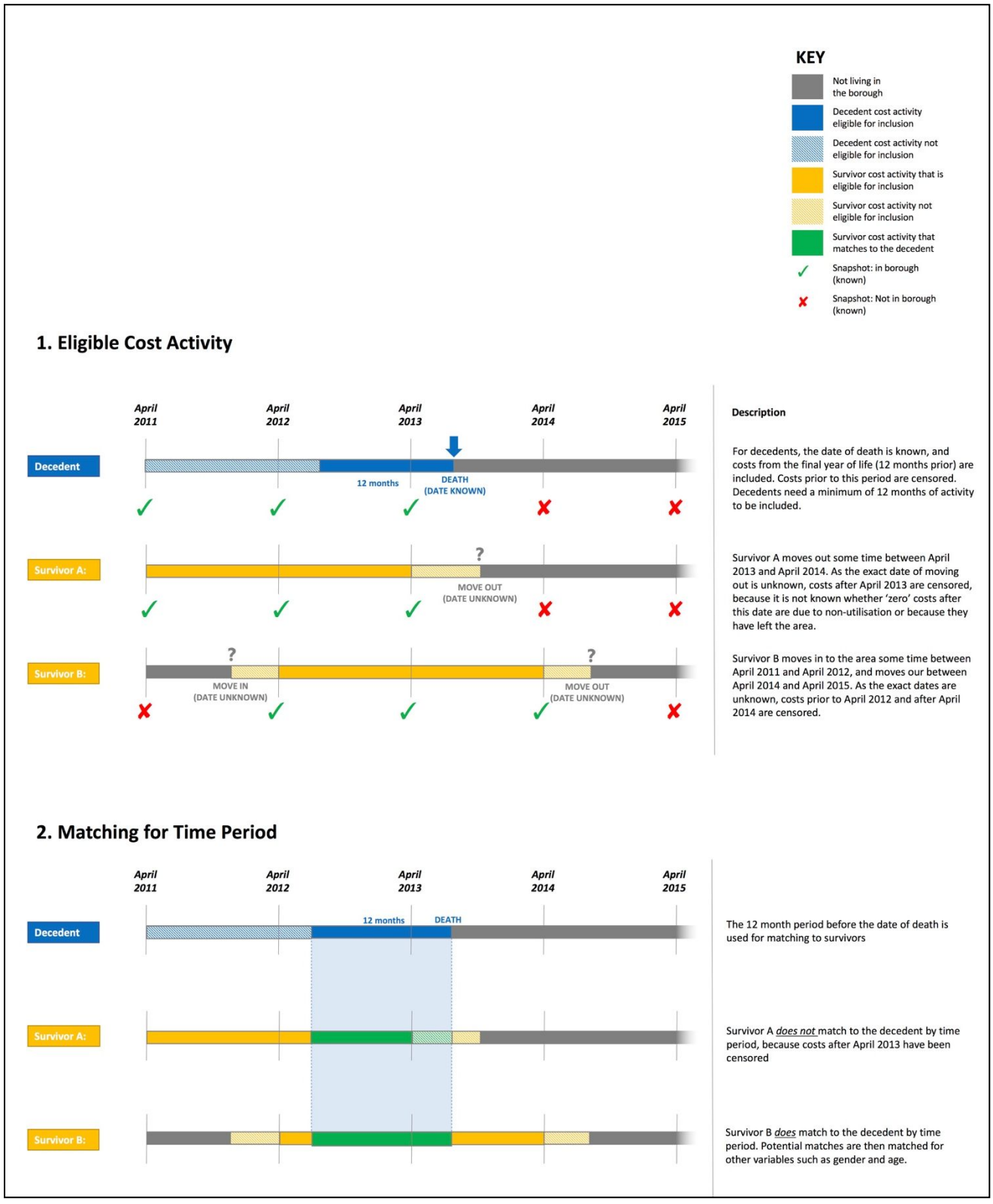
1b: Long Term Conditions

1. Atrial Fibrillation
2. Asthma
3. Cancer
4. Coronary Heart Disease
5. Chronic Obstructive Pulmonary Disease
6. Dementia
7. Depression
8. Diabetes
9. Epilepsy
10. Heart Failure
11. Hypertension
12. Hypothyroidism
13. Mental Health
14. Palliative Care
15. Stroke
16. Learning Difficulty

This list was created through consultation with clinical leaders when building the Barking and Dagenham dataset in 2016.

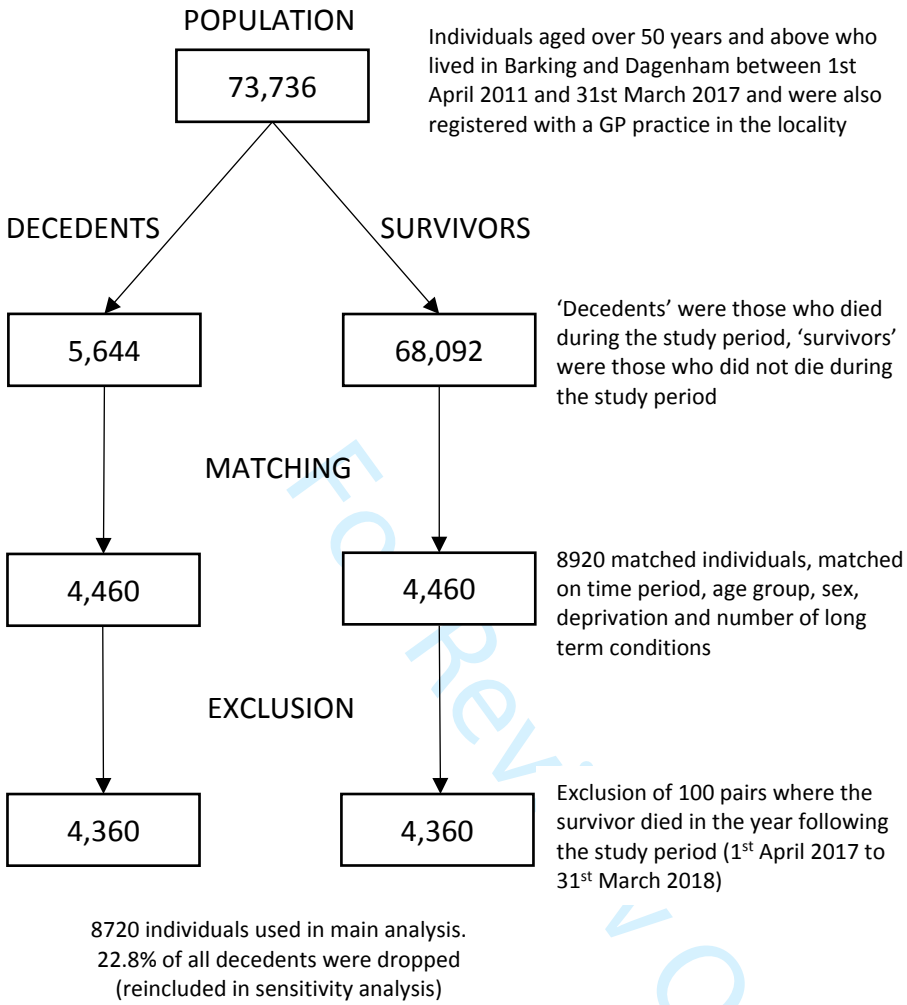
APPENDIX 2: Matching and population flow diagram

2a: Matching



Full details of the matching algorithm are available here: https://osf.io/jpf2z/.

2b: Population flow diagram



APPENDIX 3: Matching Results and Sensitivity Analysis

		MATCHED SURVIVORS (n = 4360)	*MATCHED DECEDENTS (n = 4360)*	*ALL DECEDENTS (n = 5564)*
Count		4,360	4,360	5644
Gender (Female)		50.9%	50.9%	52.4%
Age	50 - 59 years	10.0%	10.0%	7.8%
	60 - 69 years	16.3%	16.3%	12.6%
	70 - 79 years	25.6%	25.6%	20.6%
	80 - 89 years	36.3%	36.3%	35.8%
	90+ years	11.9%	11.9%	23.1%
Deprivation Quintile	Quintile 1 (most affluent)	21.2%	21.2%	20.8%
	Quintile 2	17.0%	17.0%	17.1%
	Quintile 3	22.9%	22.9%	24.8%
	Quintile 4	18.6%	18.6%	17.9%
	Quintile 5 (most deprived)	20.4%	20.4%	19.4%
Number of Conditions	0	10.6%	10.6%	8.7%
	1	21.2%	21.2%	17.8%
	2	25.5%	25.5%	23.1%
	3	22.1%	22.1%	21.8%
	4	12.0%	12.0%	14.3%
	5+	8.6%	8.6%	14.2%
Mean Annual Costs (£)	Unplanned Hospital Care	£891	£5,109	£5,259
	Planned Hospital Care	£667	£2,081	£2,008
	Social Care	£1,171	£2,483	£3,048
	Emergency Dept. Care	£90	£354	£362
	Primary Care	£1,036	£1,170	£1,268
	Outpatient Care	£282	£390	£362
	Total	£4,136	£11,586	£12,307

21% (n= 1184) of decedents were dropped from the analysis because there was not a match amongst the survivor cohort. A further 1.8% of decedents (n = 100) were excluded from the analysis where their matched survivor was found to have died in the year following the end of the study period (1st April 2017 to 31st March 2018). Overall, 22.8% (n = 1284) of decedents were excluded. Therefore, we performed a sensitivity analysis on all decedents (n = 5644), to assess the impact of including unmatched and excluded decedents, which resulted in little change to the mean costs of decedents.

APPENDIX 4: Full Results Tables

Table 2: Mean annual health and social care costs by age (GBP, 2016/17 prices)

Care Setting	Death Status	Age Group (years)									
		50-54	55-59	60-64	65-69	70-74	75-79	80-84	85-89	90-94	95+
Unplanned Hospital Care	Survivors	£193	£472	£425	£454	£670	£906	£974	£1,331	£1,287	£1,638
	Decedents	£4,013	£5,823	£5,302	£5,176	£5,433	£5,476	£5,160	£4,867	£4,752	£3,479
Planned Hospital Care	Survivors	£287	£446	£326	£542	£800	£713	£728	£781	£665	£1,102
	Decedents	£2,260	£2,140	£2,710	£2,230	£1,966	£2,152	£2,140	£2,062	£1,415	£1,640
Social Care	Survivors	£252	£108	£110	£314	£611	£765	£1,037	£2,040	£3,228	£3,358
	Decedents	£1,386	£776	£1,069	£1,181	£1,453	£1,988	£2,515	£3,740	£4,883	£6,443
Emergency Dept. Care	Survivors	£43	£47	£53	£61	£70	£89	£107	£113	£121	£156
	Decedents	£325	£377	£374	£352	£374	£357	£361	£351	£323	£289
Primary Care	Survivors	£564	£692	£771	£871	£991	£1,199	£1,195	£1,164	£1,083	£925
	Decedents	£726	£821	£944	£1,077	£1,063	£1,189	£1,310	£1,413	£1,231	£1,062
Outpatient Care	Survivors	£227	£212	£284	£263	£320	£342	£330	£272	£197	£95
	Decedents	£446	£500	£505	£444	£470	£476	£388	£293	£178	£140

Table 3: Mean monthly health and social care costs by time-to-death (GBP, 2016/17 prices)

Care Setting	Death Status	Months before death												
		12	11	10	9	8	7	6	5	4	3	2	1	0
Unplanned Hospital Care	Survivors	£65	£60	£73	£82	£66	£58	£58	£81	£73	£78	£77	£62	£58
	Decedents	£157	£188	£185	£188	£252	£297	£293	£363	£425	£496	£610	£745	£910
Planned Hospital Care	Survivors	£50	£58	£44	£60	£41	£37	£53	£54	£59	£47	£58	£54	£51
	Decedents	£96	£89	£109	£108	£104	£116	£130	£151	£196	£189	£254	£225	£313
Social care	Survivors	£75	£80	£82	£83	£86	£90	£90	£93	£96	£96	£98	£100	£102
	Decedents	£179	£180	£184	£190	£196	£202	£207	£214	£220	£221	£216	£204	£70
Emergency Dept. Care	Survivors	£7	£7	£6	£8	£6	£7	£6	£7	£7	£7	£8	£7	£7
	Decedents	£14	£13	£15	£15	£17	£20	£21	£25	£28	£32	£41	£46	£65
Primary Care	Survivors	£101	£48	£65	£95	£65	£91	£74	£77	£89	£67	£97	£55	£112
	Decedents	£106	£75	£91	£103	£91	£101	£95	£98	£102	£91	£100	£71	£45
Outpatient Care	Survivors	£23	£21	£22	£23	£23	£22	£21	£22	£20	£22	£21	£21	£22
	Decedents	£35	£33	£31	£34	£36	£32	£35	£35	£32	£29	£26	£19	£11

age and ageing

Revision Sheet

Manuscript title: Health and social care costs at the end of life: a matched analysis of linked patient records in East London

We thank the reviewers and the editor for their very useful comments. We believe our amendments to address them have substantially improved the robustness of the study and cohesion of the manuscript.

Editor

Point raised by referee (please summarise)	Response by author (briefly explain)	Location in text: Page and paragraph reference
Interesting study. From an international perspective, the fact that only part of social are costs were included (that is, those funded by local government, but not those privately funded), makes the findings less generalizable. Social care for frail older people is a 'mixed economy', with more than half being privately commissioned and funded. Good analysis, well presented. Results are not unexpected.	We have now added a line to address the limitation around only considering state-funded social care costs: *"It is important to note that the social care costs in our study relate only to state-funded care, and we can make no inferences about privately-funded care. 44% of care home placements are self-funded in England [26], although this figure is likely to be lower in Barking and Dagenham due to higher levels of deprivation."*	Page 9, lines 44 - 48

Referee 1

Point raised by referee (please summarise)	Response by author (briefly explain)	Location in text: Page and paragraph reference
Abstract: I question the statement 'Social care costs were more strongly age-patterned than healthcare costs'. Planned and unplanned hospital care also appear patterned by age. For these service types, the age-patterns are also differ according to survivor or decedent, which is the main focus of your analysis. I suggest this statement is either justified with detail, or re-worded/removed.	As you suggest, 'patterned' is the wrong word to use. We have removed this wording and instead described more clearly the difference in age-related patterns: *"Patients who died at older ages had higher social care costs and lower healthcare costs than younger patients in their final year of life."*	Page 1, lines 30-32
Background: Please revise your aim statement – it is not clear that you are comparing decedents with survivors and so the reference to controlling for important confounders is confusing without this clarification.	We deleted the phrase *"while controlling for important confounders"* from this sentence	Page 3, lines 42-43
Methods: Please justify the decision to include only those aged 50 years or above.	Deaths in the under 50 population are more likely to relate to unnatural causes of death (accidents, suicide, etc.) whereas we aimed	

	to establish the end of life costs associated with natural causes of death. Therefore we restricted the study to the over 50 population, which represented over 90% of all deaths in Barking and Dagenham. *"We restricted the study to this age group because in younger age groups deaths are more likely to relate to unnatural causes, such as accidents and suicide."*	Page 4, lines 15-16
Please include clear definitions of the care settings (perhaps in the appendix), for example how does emergency care differ from unplanned hospital care?	We have added a table that provides clear definitions of the care settings in Appendix 1a.	Page 15, lines 11-27
For those 'survivors' identified within the final year of data collection e.g. 2017, it is possible that some matched and included in the analysis were in fact in the final year of life, but their death occurred within a year after the data collection period (i.e. after March 31st 2017). Please describe steps taken to mitigate against this.	Thank you for picking up on this potential source of bias. Since our original submission, deaths data became available for 2017/18, and so we were able to amend the analysis to exclude matched survivors who died in the 12 months following the study period. Where this occurred (100 instances out of 4460 matched pairs in total) we have now excluded these pairs from the analysis. This has not significantly altered the studies' findings or conclusions; indeed, the results are very similar. However, this approach addresses what is a potential source of bias, and makes the methodology more robust.	Methods: page 5, lines 9 – 12 Appendix 2b: page 17
I suggest including the ethics statement in the methods section of the manuscript for transparency, as this is an important consideration.	The ethics statement has been moved from the end of the manuscript to the end of the methods.	Page 5, lines 34-42
Results In Figures 1 and 2 the headings unplanned and planned care should include the word 'hospital' for clarity.	We have amended the figure headings to include the word 'hospital', and also added the word 'department' to emergency care – in keeping with the new description of care settings in Appendix 1a.	Figures on page 7 and page 8
Figures 1 and 2 are of poor quality resolution and require attention.	We believe this relates to image compression when the manuscript pdf is generated. In the resubmission we have included original high quality image files separately from the manuscript. Do get back to us if this remains an issue.	Figures on page 7 and page 8
Discussion The use of the word 'increase' in the opening sentence 'Health and social care costs increased in the final year across all care settings by £7360 in total', suggests that the comparison is on the same individuals over time. In fact the analysis shows higher costs of care to people in the last year of life compared to matched individuals who are not yet in their last year of life. I think this distinction is important and would allow the reader to interpret appropriately (also in the key points).	Throughout the manuscript we have changed reference to the "costs increase" to "additional/higher costs" in people in their final year of life compared to those not in their final year, which we hope makes this clearer.	Throughout manuscript
The sentences on page 8, lines 28-30 'Our findings suggest that the healthcare component to care at the end of life is unlikely to increase with population ageing' is indefensible from this analysis. Mean trends in end of life emergency admissions are rising –	The original statement about healthcare costs at the end of life not increasing with population aging was too strong. We have therefore amended the statement to follow directly from our analysis; that death at older ages results in a higher relative proportion of	

Numbers of deaths occurring in older age are rising, so I would contend that we are expecting a rise in end of life hospital utilisation, and therefore also a rise in the associated costs. Although I do agree that demand for social care services are likely to rise. Please revise this statement.	care received relating to social care compared to healthcare (though both may increase as you suggest). *"Our findings also suggest that an ageing society is likely to lead to a relative shift in care demands at the end of life towards social care, which is important given the current scarcity of funding for social care in England"*	Page 10, lines 28-30
Key points Key point: 'Social care costs are more strongly influenced by age than time to death' does not appear to be supported by the data. The age, gender, and diagnosis matched decedents had significantly higher social care costs in the final year of life than 'survivors', suggesting that regardless of age, being in the last year of life means considerably higher care costs than those who are not in their final year. Please revise.	Yes, determining the relative importance of age and time to death was not the main focus of the study and our analysis was not geared to answer this. What instead we can comment on is the interesting difference in age-patterns between healthcare and social care costs at the end of life. *"As age of death increases, the proportion of care costs relating to social care relative to healthcare increases."*	Page 2, lines 17-19

Referee 2

Point raised by referee (please summarise)	Response by author (briefly explain)	Location in text: Page and paragraph reference
This manuscript looks at health and social care costs at the end of life for a relatively small area in England, which is also my main concern. There is no justification in the paper, why this area has been chosen for the analysis. Are findings generalisable to the whole of the UK?	We wanted to explore social care costs at the end of life, but there are no national datasets available where social care data is linked to health care data at a patient level. Barking and Dagenham is one of the first areas in England to have linked data available across the domains of care we wanted to explore. We have amended the description of the data source to justify this decision: *"The source was a novel patient-level linked dataset including events from local government services, health providers and health commissioners in the area"* Inevitably, the findings from a single area may not be fully generalizable to the whole of the UK. As described in the paper, for example, there are demographic differences between the study population and national population. Health and social care policy varies amongst the devolved nations, but our papers' findings are likely to be more generalizable to England as a whole, as there is limited scope for local areas to deviate from national directives on eligibility for different types of care, and all areas in England have been subject to similar funding pressures in recent history.	Page 4, lines 20-22
Page 2, line 12: Am I right in thinking that you did not include any information from 31st March 2016 to 31st March 2017 in your analysis, otherwise you would not be able to determine that a survivor was not in their last year of life? In general, I would like to see a bit more information on the dataset and the time periods covered and population included.	As described above in response to reviewer 1: Since our original submission, deaths data became available for 2017/18, and so we were able to amend the analysis to exclude matched survivors who died in the 12 months following the end of the study period (2011 to 2017). This is now described in the methods paragraph on matching.	Methods: page 5, lines 9 – 12

	We have also added a flow diagram in appendix 2b that clearly explains the population, time periods and exclusions.	Appendix 2b: page 17
Page 3, line 6: Could you describe the method or possibly name it?	We have more clearly described the matching method in the manuscript, and provide a link to the algorithm itself. *"Second, we matched survivors and decedents whereby participants with the fewest matches were assigned first in order to maximise the number of total unique matches. The matching algorithm is available here: https://osf.io/jpf2z/."*	Page 5, lines 4-7
How did you address any residual confounding that the matching did not control for?	Residual confounding is a potential limitation of this study, as with most observational studies. In this case, the main source of residual confounding is likely to be differences in morbidity that are not captured by the count of long-term conditions. Although we have included several important confounders in our analysis we do accept that survivors and decedents may differ in ways we have not measured. We have included these points in the discussion. We would welcome the reviewer's suggestions for anything further in the analysis or interpretation we should consider to mitigate the risk from residual confounding to the validity of our findings.	Page 9, lines 53-58
Page 7, line 27: I was wondering whether it would be more appropriate to include confounders and effect modifiers in a regression framework; i.e. age, time to death and an interaction between the two. In order to be able to say anything about the size of the effect of age or TTD on costs, you would most likely need to run some form of regression, otherwise, I am not entirely sure how you would justify the claims you are making in that section.	Yes, determining the relative importance of age and time to death was not the main focus of the study and our analysis was not geared to answer this. Our original claims here were too strong, and might have required a regression framework. This would complicate the analysis and require further elaboration, so we have decided not to include it. Instead we have deleted the claim about effect modification, and deleted discussion of the relative importance of age and proximity to death. This section on comparison to prior literature now reads: *UK-based studies that exclusively consider healthcare expenditure show that costs increase with age among survivors and decrease with age among decedents [5,9,26]. Our analysis reconfirmed these findings for healthcare costs, but additionally found that social care costs, by contrast, increase with age among both survivors and decedents. This is similar to studies from other countries which have found that social care (or equivalent) costs are more age-dependent than hospital costs once accounting for time-to-death [11–15].*	Page 9, lines 25-33
Policy implications: Your findings are in line with findings from other studies and it is well established that social care costs tend to decrease in the final month due to patients being admitted to hospital, so I would like to see a stronger argument about what your study is adding to the existing evidence base.	While there have been other studies in England of inpatient hospital costs at the end of life, most of these exclude costs of primary care and social care. These are particularly important given the recent UK health policy agenda around integrated care planning and shared budgets. The only other studies we found that had included social care costs are	Background, Page 3 and Discussion, Page 9

	now outdated (predating government austerity and the 2012 health policy reforms) and provided mainly descriptive analyses, whereas the matching of decedents to survivors allowed us to report the true costs associated with the end of life. This matching approach also allowed for clearer visualization of the data which can be more easily interpreted by policymakers.	

Abstract

Abstract word limit: 250
Currently: 247

Background: Care in the final year of life accounts for 10% of inpatient hospital costs in England. However, there has been little analysis of costs in other care settings. We investigated the publicly funded costs associated with the end of life across different health and social care settings.

Method: We performed cross-sectional analysis of linked electronic health records of residents aged over 50 in a locality in East London, England, between 2011 and 2017. Those who died during the study period were matched to survivors on age group, ~~gender~~sex, deprivation, number of long term conditions and time period. Mean ~~care~~ costs were calculated by care setting, age, and months to death.

Results: Across 8~~7~~920 matched patients, the final year of life was associated with £~~an increase in mean costs of £7359~~7450 (95%CI £7086~~7012~~ - £7842~~7720~~, p<0.001) of additional health and care costs, 57% of which ~~was~~ related to ~~due to~~ unplanned hospital care. While costs increased sharply over the final few months of life in emergency and inpatient hospital care, in ~~less~~non-acute settings costs were less concentrated ~~they were more flat and even declined~~ in this period. ~~Social care costs were more strongly age-patterned than healthcare costs.~~ Patients who died at older ages had higher social care costs and lower healthcare costs than younger patients in their final year of life.

Conclusions: The large proportion of costs relating to unplanned hospital care suggests that end-of-life planning could direct care towards more appropriate settings and lead to system efficiencies. ~~Social care costs increase with age after accounting for proximity to death, which has implications for an aging population.~~ Death at older ages results in an increasing proportion of care costs relating to social care than to healthcare, which has implications for an aging society.

Key Points (3-5)

- ~~A large proportion of acute care costs are known to occur at the end of life, although less is known for other care settings.~~ The end of life period is associated with high hospital care costs, but less is known about costs in other care settings.
-
- We examined cost patterns at the end of life across different care settings in an East London locality.
- ~~Care~~ Health and care costs were ~~increased by £7360~~£7450 ~~on average in~~for patients in their final year of life ~~and 57% of this was due to unplanned hospital care~~compared to those not in their final year.
- Most costs at the end of life related to unplanned hospital care, where costs were more highly concentrated in the final months
- ~~Over the final months, acute care costs increased sharply while those in less acute settings are relatively flat or decline.~~
- ~~Social care costs are more strongly influenced by age than time-to-death, which may have implications for an aging society.~~As age of death increases, the proportion of care costs relating to social care relative to healthcare increases.

Keywords:

end-of-life, ageing, dying, costs, expenditure

Current word count: ***2523***

Background

Controlling public expenditure on healthcare related to population ageing and growing health needs is one of the most pressing health policy objectives in England and other high-income countries. Per capita health spending rises with age, with annual costs of £2,300 per person at age 60 and £10,000 at 90 [1]. However, this hides the underlying drivers of healthcare expenditure. The 'red herring' hypothesis, first proposed by Zweifel et al [2], states that it is proximity to death, rather than age per se, that drives healthcare expenditure, and age only appears to explain expenditure because elderly individuals are more likely to be in the period approaching death. The large increase in costs during the end of life period has been confirmed across multiple studies and settings [3,4].

In England, inpatient hospital care in the final year of life has been estimated as £2.5bn, or 10.4% of total expenditure in this setting [5]. Other studies have also found high costs associated with the end of life period [6–9], but are usually limited to hospital~~acute~~ settings and exclude community care and social care. Social care refers to support for the activities of daily living (for example, via home visits or residency in a care home), which people are more likely to require as they age. Internationally, studies have found that long term social care expenditures are more greatly influenced by age than proximity to death, unlike hospital~~acute care~~ expenditure [10–15]. There is little comparable literature in England because healthcare and mortality data has historically not been linked to social care data. Analysis using linked data found that the time-to-death effect applied more strongly for hospital costs than social care costs [17,18].

Unlike healthcare, which is free at the point of use via the National Health Service (NHS), social care is means-tested in England. State funding is only available to those with the highest need and the lowest means [18], with different funding streams and care providers to those found in the NHS. Understanding end-of-life costs across these settings is crucial as the health system attempts to reduce the costs associated with unplanned hospital care by increasing care integration between settings [19]. We therefore investigated the system-wide costs associated with the end of life period ~~while controlling for important confounders~~, and explored patterns in end of life costs by care setting, age, and time-to-death.

Methods

Setting and population

Barking and Dagenham is a densely populated urban locality in East London, England, with 210,700 residents. The area has a younger average age, more ethnic diversity and high social disadvantage compared to the rest of the country [20]. The study population ~~included all confirmed residents of the locality at any point between~~was defined as individuals aged 50 years and above who lived in Barking and Dagenham between 1st April 2011 and 31st March 2017 ~~who~~ and were ~~also~~ registered with a GP practice in the locality. We restricted the study to this age group because in younger age groups deaths are more likely to relate to unnatural causes, such as accidents and suicide. ~~The study was restricted to patients aged over 50 and above during the study period.~~ This resulted in a study population of 73,736 individuals, of which 5,644 had died over the study period.

Data sources

The source was a novel patient-level linked dataset including events from local government services, health providers and health commissioners in the area. The dataset includes patient demographics, ~~service utilization,~~ location of residence, ~~and~~ mortality information and service utilization across different settings, which are defined in Appendix 1a. Costs ~~have been~~were assigned to each unit of activity, using different methods by setting. Primary care costs were estimated from the 2016/17 Personal Social Services Research Unit manual of reference costs [21], ~~whereby 2016/17 unit costs were applied to~~with £38 per general practitioner visit and £10.50 for visiting another healthcare professional ~~family doctor (£38), and non-doctor attendances (£10.50). For prescriptions, a~~Average costs per prescription by primary care practice were applied to each prescription. Secondary care unit costs were taken from the ~~national tariff prices for Healthcare Resource Groups~~NHS National Reference Costs [22]**,** which are used for calculating ~~the reimbursement of healthcare providers~~ payments from commissioners to hospitals in the NHS. Local-government-funded social care costs were obtained from data that lists the weekly billed cost for each care package provided (and therefore allowed for weekly updates to that value if package~~s~~ revisions were made). All costs in the study period were inflated to 2016/17 prices using the Hospital and Community Health Services inflation index [21]**.**

Confounders were variables that we expected to be associated with mortality risk and independently predict healthcare expenditure. We extracted sex, age (in five-year categories), deprivation and morbidity [23]. Local deprivation quintiles were calculated from the 2015 English Index of Multiple Deprivation scores for each patient's neighborhood of residence [24]. Morbidity was taken as the count of up to sixteen diagnosed long term conditions from primary care records [Appendix 1b], with those with five or more grouped.

The dataset included the month but not the day of death. Where care episodes occurred in the month of death, we used the date of the last recorded care episode as the date of death. Where no care episode occurred in the month of death, we used the first day of the month.

Matching

People in their final year of life ('decedents') differ in many respects to those not in their final year of life ('survivors'), with the decedents being older and having a greater degree of morbidity~~, such that the mean costs of the two groups are not directly comparable~~. We matched decedents to survivors ~~across a number of variables in order to control for these confounders. The matching process was conducted in~~using a two-~~-~~stage process, described in more detail in~~s~~ Appendix 2a. First, we identified all potential matches where decedents and survivors had the same ~~gender~~sex, age group, deprivation quintile, number of long term conditions, and ~~were~~ where the survivor was known to be resident in the locality during ~~the same time period~~the decedent's final year of life. Second, we matched survivors and decedents whereby participants with the fewest matches were assigned first in order to maximise the number of total unique matches. ~~using a method designed to maximize the number of 1:1 matches~~ The matching algorithm is available here: https://osf.io/jpf2z/. No ~~survivors or decedents~~patients were included ~~in the analysis~~ more than once. Decedents who could not be matched were excluded ~~from the main analysis~~. Matched pairs from the final year of the study period were also excluded where the matched survivor was found to have died in the subsequent twelve months (1st April 2017 to 31st March 2018), to prevent misclassification. These exclusions are depicted as a flow diagram in Appendix 2b. ~~In a sensitivity analysis, we examined the effect of including unmatched decedents in the decedent group.~~ By comparing the same time periods of activity between matched pairs, we controlled for potential period effects over the six-year ~~s~~~~study timeframe~~, ~~potential~~ seasonal effects ~~that might have occurred~~ (such as higher costs in winter months), and changes in prices that were not already accounted for by the overall inflation index.

Analysis

We calculated the mean difference in c~~C~~osts in the final year of life by setting ~~were calculated as the mean difference in costs between survivors and decedents~~for decedents and survivors, with bootstrapped confidence intervals for paired differences and significance testing via the Wilcoxon signed-rank test. ~~, as cost data was skewed.~~ We also disaggregated mean annual costs by age group, and calculated mean monthly costs over the final twelve months before the date of death (or for survivors, the date of the death of their matched decedent). To help visualise patterns, we added lines to scatterplots using locally weighted scatterplot smoothing. In a sensitivity analysis, we examined the effect of including unmatched decedents on health and care costs. All data processing, matching and analyses were conducted using R version 3.5.1.

Ethics

The dataset is not publicly available. It is hosted in the Barking and Dagenham, Havering and Redbridge NHS Accredited Data Safe Haven and contains routinely collected, retrospective, pseudonymised data. It was created for research purposes with ongoing governance and oversight provided by the Barking and Dagenham, Havering and Redbridge Information Governance Steering Committee. This study meets national guidelines set out by the Research Ethics Service for the National Health Service in England. No furthers ethics approval was required (http://www.hra-decisiontools.org.uk/ethics/resultN2.html).

Results

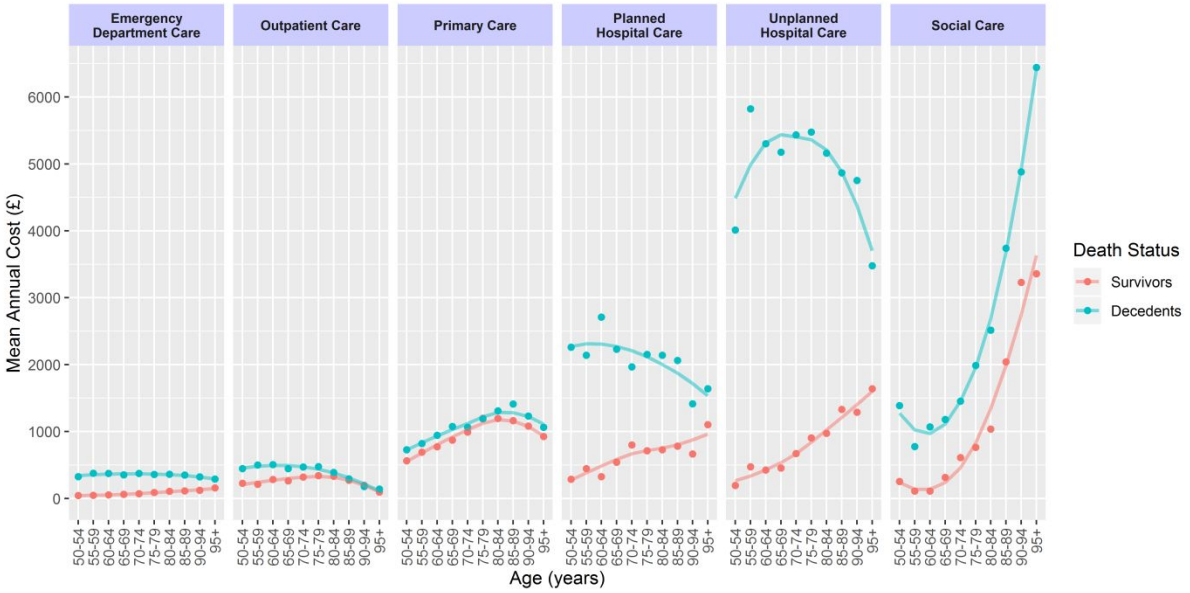
Table 1: Mean annual costs in the final year of life by care setting (GBP, 2016/17 prices) ~~(with bootstrapped 95% confidence intervals and p-values calculated via the Wilcoxon signed-rank test)~~

Care setting	Mean annual cost - survivors	Mean annual cost - decedents	Difference (95% CI)	p-value	% of total cost associated with the end of life
Unplanned Hospital Care	£891	£5,109	£4,218 (4017 – 4434)	p < 0.001	56.6%
Planned Hospital Care	£667	£2,081	£1,414 (1277 – 1558)	p < 0.001	19.0%
Social Care	£1,171	£2,483	£1,312 (1092 – 1546)	p < 0.001	17.6%
Emergency Department Care	£90	£354	£264 (252 – 277)	p < 0.001	3.5%
Primary Care	£1,036	£1,170	£134 (94 – 175)	p < 0.001	1.8%
Outpatient Care	£282	£390	£108 (87 – 129)	p < 0.001	1.5%
Total	£4,136	£11,586	£7,450 (7086 – 7842)	p < 0.001	100.0%

Main results

4360 matched pairs of survivors and decedents (n = 8720) were analysed, following exclusion of ~~8920 individuals were matched, with~~ 21% of decedents who could not be matched and a further ~~excluded where an exact match could not be obtained~~1.8% decedents where the matched survivor was found to have died in the year following the study period [Appendix 2b]. Comparing paired decedents and survivors, the final year of life was associated on average with an additional cost ~~cost increase~~ of £74507~~359~~ (95%CI £70708~~612~~ - £78427~~720~~, p<0.001) [Table 1]. Additional costs at the end of life were found across all care settings~~All care settings demonstrated a statistically significant increase in costs in the final year of life (p<0.001)~~, but unplanned hospital care was the largest contributor, ~~with an increase of~~accounting for £42184~~214~~ (57%) ~~representing 57%~~ of the overall increase in costs. Large ~~increases~~ differences in costs were also seen for planned hospital care (£1414) and social care (£1312~~269~~) ~~and planned care (£1384)~~ with smaller ~~increases~~ differences seen for outpatient care (£108), primary care (£134~~120~~) and emergency department care (£264). Sensitivity analysis using all decedents (n = 5644), including all those which were ~~unmatched~~excluded, resulted in similar baseline characteristics ~~across the variables studied~~ and returned similar mean costs to the main analysis~~matched decedents~~ [Appendix 3].

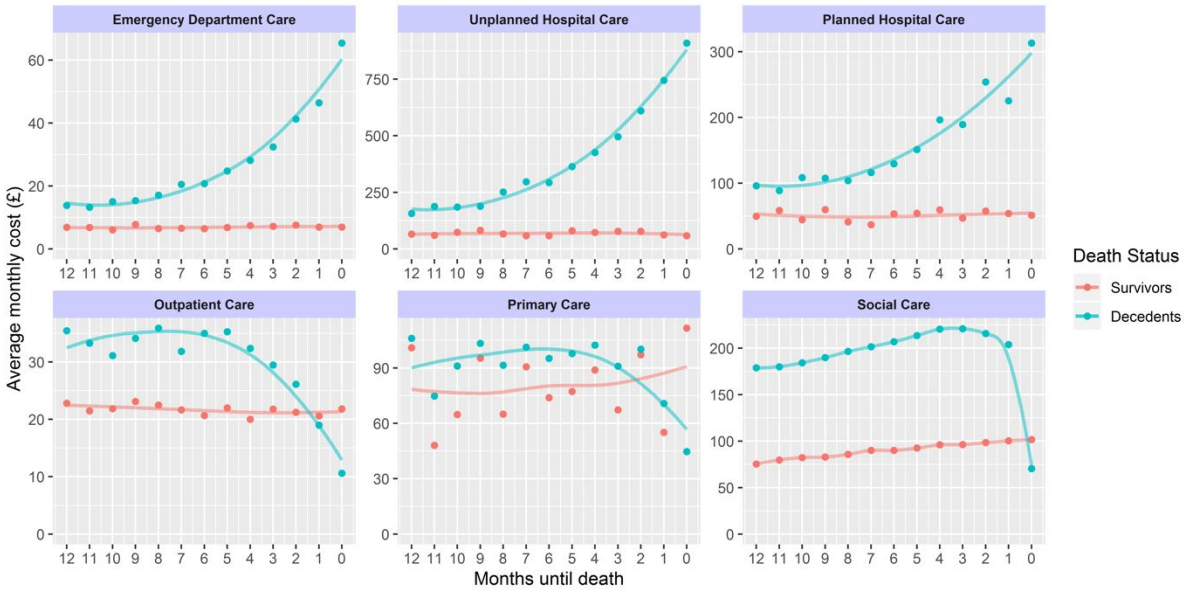
Figure 1: Health and social care costs by death status and age. *A table with the numerical values of the data represented in Figure 1 is provided in Appendix 4.*



Annual costs by age

~~Care~~ Health and care costs were higher in decedents than survivors across all ~~care~~ settings and age groupss, but ~~within each group the effect of age differed across settings~~the age-related patterns in costs and end-of-life care costs differed by setting [Figure 1]. In decedents, costs decreased across most healthcare settings as age increased beyond age 75, particularly for unplanned and planned hospital care, and outpatient care. In survivors, healthcare costs ~~tended to increase~~increased ~~gradually~~with age for emergency department care, and unplanned and planned hospital care, while decreasing for outpatient care and primary care beyond age 75 years and 85 years respectively. Social care costs increased dramatically with age in both decedents and survivors.

Figure 2: Health and social care costs for decedents and survivors by time-to-death (for decedents) and matched time period (for survivors). *A table with the numerical values of the data represented in Figure 2 is provided in Appendix 4.*



Monthly costs by time-to-death~~setting~~

The change in monthly costs during the final year of life also varied by care setting [Figure 2]. In acute settings (emergency department care, ~~and~~ planned and unplanned hospital care), monthly costs in the month of death were roughly three times higher than costs twelve months before death, with a sharp increase over the last few months. In non-acute settings (outpatient care, ~~and~~ primary care and social care), ~~,~~ costs in the final year of life ~~are~~ were still higher overall than for survivors, but with a different pattern from month to month, with costs decreasing over the final few months. There ~~is~~ was a particularly steep decline in social care costs over the last month of life.

358 words

Discussion

Main findings

In the over 50 years population of a locality in East London, health and care costs were £7,450 higher for patients in their final year of life (£11,586) compared to those not in their final year (£4,136). ~~Health and social care costs increased in the final year across all care settings, by £7360 in total~~. Unplanned hospital care accounted for the majority of this difference ~~increase~~. ~~Large increases in the final year of life were also seen in planned hospital care and social care~~Patients in their final year of life also had substantially higher costs relating to planned hospital admissions and social care. ~~In contrast to healthcare costs, which decreased with age among decedents, social care costs rise greatly with age in both survivors and decedents~~ As age of death increased, healthcare costs in the final year of life decreased, while social care costs continued to increase as for survivors. Monthly costs by time-to-death varied ~~Cost patterns at the end of life by month differed~~ by setting: while costs in acute settings ~~care costs~~ rose steeply during the last few months, costs in ~~care in less~~ non-acute settings ~~settings dipped~~ were less concentrated over this period.

Comparison with other literature

The only other studies based in England to consider both health and social care costs together arrived at mean costs per person of £10,130 [16] and £9,437 [17] in the final year of life. These are similar figures to ours (£11,58611,610) after accounting for inflation, although these older studies did not include primary care costs. ~~Our analysis by age group lends weight to the red herring hypothesis, that healthcare costs are more greatly influenced by proximity to death than age [2,3] but we also note that age seems to be an effect modifier in the relationship between healthcare costs and proximity to death: among decedents healthcare costs actually decreased with age, which has also been found in other studies~~ UK-based studies that exclusively consider healthcare expenditure show that costs increase with age among survivors and decrease with age among decedents [5,9,26]. ~~Furthermore, the hypothesis did not apply to social care costs, which were more greatly influenced by age in our study, similar to findings from other countries~~ Our analysis reconfirmed these findings for healthcare costs, but additionally found that social care costs, by contrast, increase with age among both survivors and decedents. This is similar to studies from other countries which have found that social care (or equivalent) costs are more age-dependent than hospital~~acute healthcare~~ costs once accounting for time-to-death [11–15].

Strengths and limitations

A strength of our analysis is that we matched survivors to decedents according to several known confounders, meaning that the cost difference is more likely to be related to the end of life. ~~Also, w~~We also included time period as a matching criterion, which improved on existing analyses by ~~addressing~~ controlling for ~~the potential influence of~~ period effects ~~or~~ and seasonality. While ~~the matching process did result~~resulted in 22.821% of all decedents were ~~being~~ excluded ~~from the main analysis~~, sensitivity analysis with all decedents arrived at similar mean costs [Appendix 3].

It is important to note that the social care costs in our study relate only to state-funded care, and we can make no inferences about privately-funded care. 44% of care home placements are self-funded in England [26], although this figure is likely to be lower in Barking and Dagenham due to higher levels of deprivation. Data were also not available for mental health services and community care, which would have provided a more complete picture of system-wide costs. The Barking and Dagenham population is younger, more ethnically diverse and more deprived than the England average [20], which may limit generalization of our results. ~~Primary care costs were only available at a month-level rather than day-level, and so this activity was assumed to occur on the first day of each month. This means that some of the primary care costs may have been attributed to the wrong month, affecting the analysis of costs by months before death.~~ Finally, there may be residual confounding after matching survivors and decedents. In particular, we matched on the number of long-term conditions, but the groups may differ in terms of the type, severity or combination of conditions, and definitions of multimorbidity continue to evolve in the literature. We also did not analyze place of death which may be an important determinant of costs in the final month.

Policy implications

Understanding care use by setting over the final twelve months could be used to better align care in this period to patient wishes. ~~A majority of~~Most patients prefer to die in their usual place of residence [27], yet in our study, there was a steep rise in emergency and unplanned hospital costs in the final few months of life. Social care costs on the other hand, reduced suddenly in the final month, likely because patients were being admitted to hospital. Better end-of-life planning might reduce this cost-shifting by allowing recipients of social care to die at their usual place of residence, preventing the need for acute hospital admissions, as has been demonstrated in some studies [28]. Such planning might also reduce planned hospital costs, which increased sharply in the final months, potentially ~~signifying an overdependence on~~ reflecting unwarranted elective investigations and procedures on patients for whom end-of-life planning may have been more appropriate. There is some economic evidence that end-of-life planning leads to ~~overall~~ costs savings, at least for ~~certain populations~~some patients, such as those with dementia or living in care homes [29].

~~Given policy moves to improve health system efficiency across local areas, it is important to note the large degree of unplanned care costs occurring at the end of life~~The large costs associated with unplanned hospital admissions at the end-of-life are important in the context of current UK policy to introduce shared planning and budgets across health and care settings [30]. In our study, costs associated with care in the final year of life accounted for around 18% of the overall health and social care expenditure in the over-50 age group (based on the average costs in our results multiplied by the size of the population), ~~. If extrapolated to total annual UK expenditure on health and social care across all ages this represents around £29bn,~~ highlighting the importance of the end-of-life period to health system planning. Our findings also suggest that ~~the healthcare component to care at the end of life is unlikely to increase with population ageing. By contrast,~~ an ageing society is likely to lead to a relative shift in care demands at the end of life towards social care ~~increase demand for social care services~~, which is important given the current scarcity of funding for social care in England [18].

Conclusions

We demonstrated how costs of care at the end of life in England break down across settings, including social care. The final year of life is associated with high health and care costs ~~for health and social care services~~, a majority of which relate to~~are in~~ unplanned hospital care, and in those dying at older ages, social care costs become more significant~~social care costs are more strongly age-patterned than healthcare costs~~. Understanding patterns of care use at the end of life across different settings may be key to understanding interventions designed to keep patients out of hospital in their final months, to the benefit of patients, their families and the efficiency of the system.

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Declarations

The authors declare no conflicts of interest in this work.

~~Ethics~~

~~The dataset is not publicly available. It is hosted in the Barking and Dagenham, Havering and Redbridge NHS Accredited Data Safe Haven and contains routinely collected, retrospective, pseudonymised data. It was created for research purposes with ongoing governance and oversight provided by the Barking and Dagenham, Havering and Redbridge Information Governance Steering Committee. This study meets national guidelines set out by the Research Ethics Service for the National Health Service in England. No furthers ethics approval was required (http://www.hra-decisiontools.org.uk/ethics/resultN2.html).~~

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Appendix

APPENDIX 1:

1a: Care Setting Definitions

Care Setting	Definition
Unplanned Hospital Care	Unscheduled (non-elective) care following inpatient admission, funded via the NHS
Planned Hospital Care	Scheduled (elective) procedures, investigations and care funded via the NHS
Social Care	Local government funded care to support activities of daily living, either via home visits or residency in care homes
Emergency Department Care	All types of accident and emergency (A&E) attendances funded via the NHS
Primary Care	NHS-funded care delivered in general practice settings, by both general practitioners (family doctors) and other healthcare professionals, including prescription costs
Outpatient Care	Specialist outpatient attendances funded via the NHS

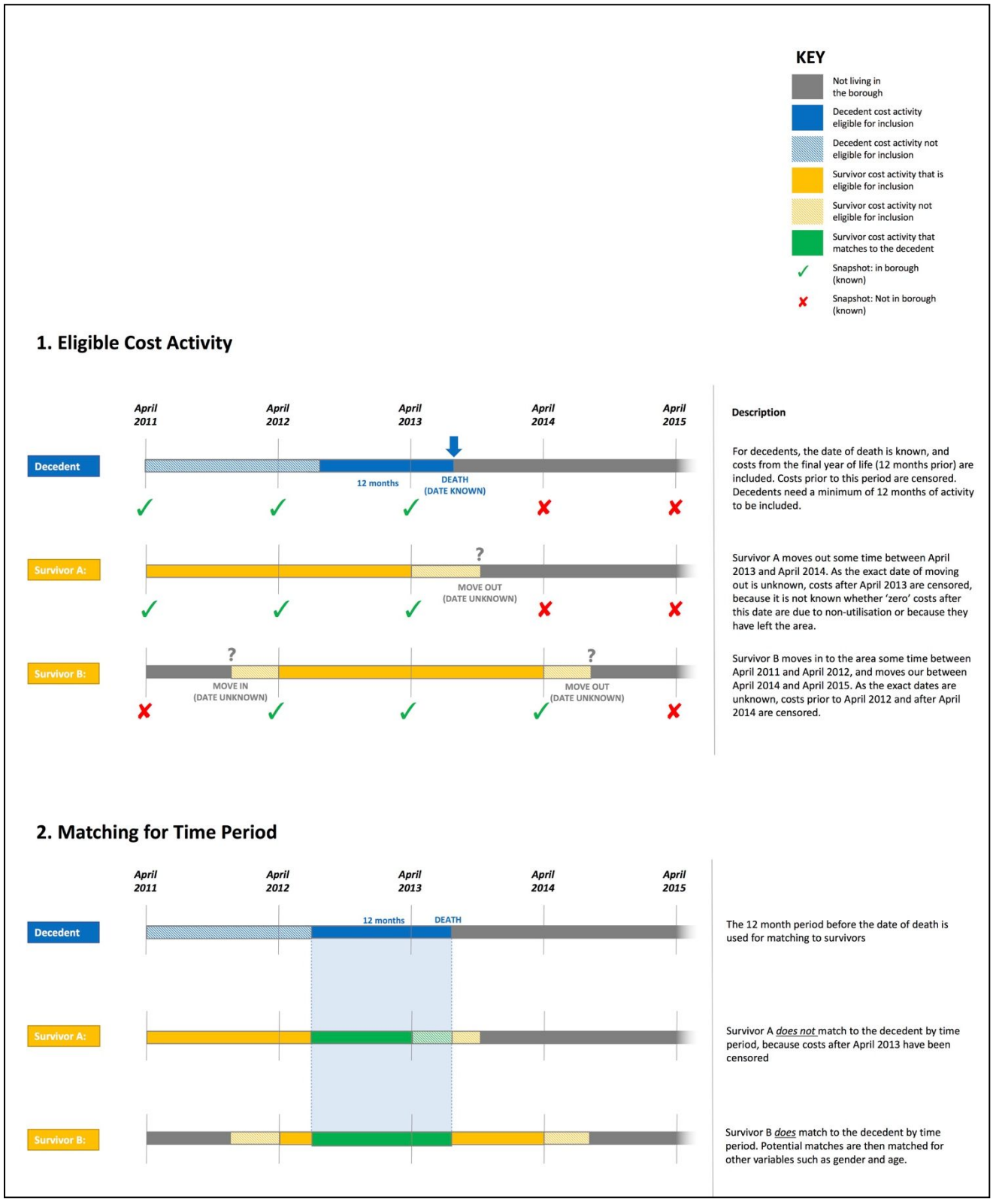
1b: Long Term Conditions

1. Atrial Fibrillation
2. Asthma
3. Cancer
4. Coronary Heart Disease
5. Chronic Obstructive Pulmonary Disease
6. Dementia
7. Depression
8. Diabetes
9. Epilepsy
10. Heart Failure
11. Hypertension
12. Hypothyroidism
13. Mental Health
14. Palliative Care
15. Stroke
16. Learning Difficulty

This list was created through consultation with clinical leaders when building the Barking and Dagenham dataset in 2016.

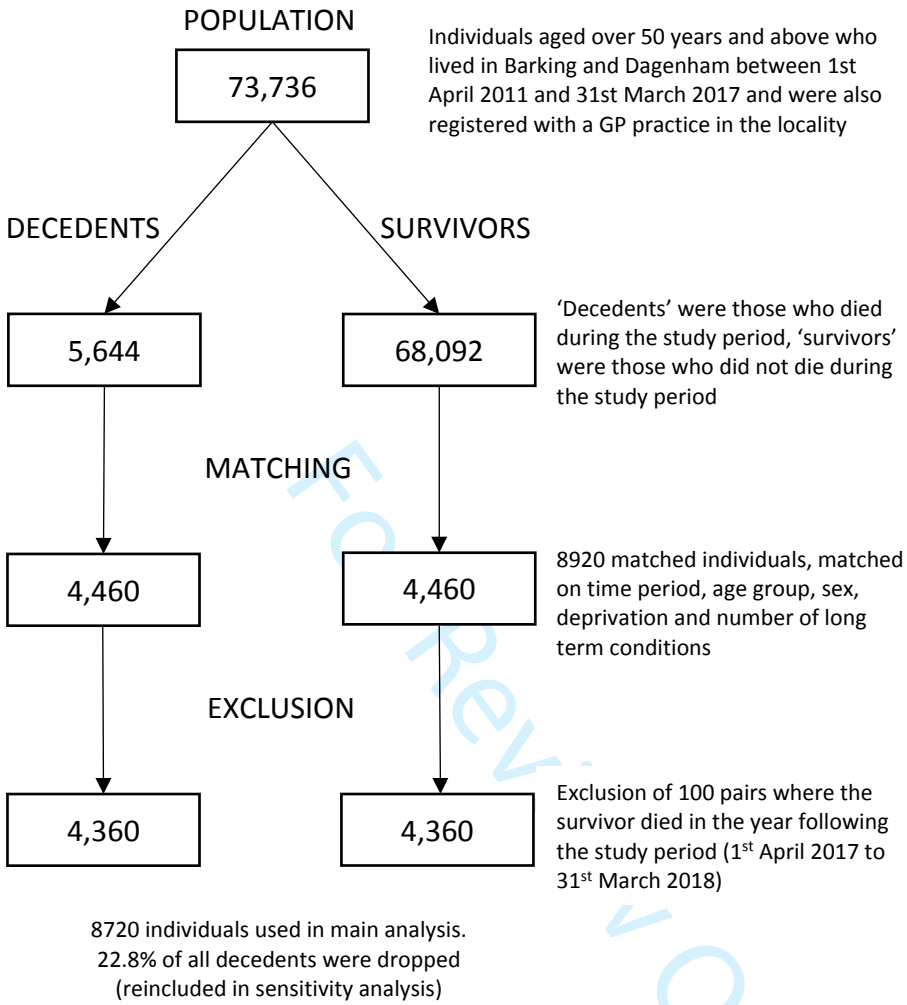
APPENDIX 2: Matching and population flow diagram

2a: Matching



Full details of the matching algorithm are available here: https://osf.io/jpf2z/.

2b: Population flow diagram



APPENDIX 3: Matching Results and Sensitivity Analysis

		MATCHED SURVIVORS (n = 4360)	*MATCHED DECEDENTS (n = 4360)*	*ALL DECEDENTS (n = 5564)*
Count		4,360	4,360	5644
Gender (Female)		50.9%	50.9%	52.4%
Age	50 - 59 years	10.0%	10.0%	7.8%
	60 - 69 years	16.3%	16.3%	12.6%
	70 - 79 years	25.6%	25.6%	20.6%
	80 - 89 years	36.3%	36.3%	35.8%
	90+ years	11.9%	11.9%	23.1%
Deprivation Quintile	Quintile 1 (most affluent)	21.2%	21.2%	20.8%
	Quintile 2	17.0%	17.0%	17.1%
	Quintile 3	22.9%	22.9%	24.8%
	Quintile 4	18.6%	18.6%	17.9%
	Quintile 5 (most deprived)	20.4%	20.4%	19.4%
Number of Conditions	0	10.6%	10.6%	8.7%
	1	21.2%	21.2%	17.8%
	2	25.5%	25.5%	23.1%
	3	22.1%	22.1%	21.8%
	4	12.0%	12.0%	14.3%
	5+	8.6%	8.6%	14.2%
Mean Annual Costs (£)	Unplanned Hospital Care	£891	£5,109	£5,259
	Planned Hospital Care	£667	£2,081	£2,008
	Social Care	£1,171	£2,483	£3,048
	Emergency Dept. Care	£90	£354	£362
	Primary Care	£1,036	£1,170	£1,268
	Outpatient Care	£282	£390	£362
	Total	£4,136	£11,586	£12,307

21% (n= 1184) of decedents were dropped from the analysis because there was not a match amongst the survivor cohort. A further 1.8% of decedents (n = 100) were excluded from the analysis where their matched survivor was found to have died in the year following the end of the study period (1st April 2017 to 31st March 2018). Overall, 22.8% (n = 1284) of decedents were excluded. Therefore, we performed a sensitivity analysis on all decedents (n = 5644), to assess the impact of including unmatched and excluded decedents, which resulted in little change to the mean costs of decedents.

APPENDIX 4: Full Results Tables

Table 2: Mean annual health and social care costs by age (GBP, 2016/17 prices)

Care Setting	Death Status	Age Group (years)									
		50-54	55-59	60-64	65-69	70-74	75-79	80-84	85-89	90-94	95+
Unplanned Hospital Care	Survivors	£193	£472	£425	£454	£670	£906	£974	£1,331	£1,287	£1,638
	Decedents	£4,013	£5,823	£5,302	£5,176	£5,433	£5,476	£5,160	£4,867	£4,752	£3,479
Planned Hospital Care	Survivors	£287	£446	£326	£542	£800	£713	£728	£781	£665	£1,102
	Decedents	£2,260	£2,140	£2,710	£2,230	£1,966	£2,152	£2,140	£2,062	£1,415	£1,640
Social Care	Survivors	£252	£108	£110	£314	£611	£765	£1,037	£2,040	£3,228	£3,358
	Decedents	£1,386	£776	£1,069	£1,181	£1,453	£1,988	£2,515	£3,740	£4,883	£6,443
Emergency Dept. Care	Survivors	£43	£47	£53	£61	£70	£89	£107	£113	£121	£156
	Decedents	£325	£377	£374	£352	£374	£357	£361	£351	£323	£289
Primary Care	Survivors	£564	£692	£771	£871	£991	£1,199	£1,195	£1,164	£1,083	£925
	Decedents	£726	£821	£944	£1,077	£1,063	£1,189	£1,310	£1,413	£1,231	£1,062
Outpatient Care	Survivors	£227	£212	£284	£263	£320	£342	£330	£272	£197	£95
	Decedents	£446	£500	£505	£444	£470	£476	£388	£293	£178	£140

Table 3: Mean monthly health and social care costs by time-to-death (GBP, 2016/17 prices)

Care Setting	Death Status	Months before death												
		12	11	10	9	8	7	6	5	4	3	2	1	0
Unplanned Hospital Care	Survivors	£65	£60	£73	£82	£66	£58	£58	£81	£73	£78	£77	£62	£58
	Decedents	£157	£188	£185	£188	£252	£297	£293	£363	£425	£496	£610	£745	£910
Planned Hospital Care	Survivors	£50	£58	£44	£60	£41	£37	£53	£54	£59	£47	£58	£54	£51
	Decedents	£96	£89	£109	£108	£104	£116	£130	£151	£196	£189	£254	£225	£313
Social care	Survivors	£75	£80	£82	£83	£86	£90	£90	£93	£96	£96	£98	£100	£102
	Decedents	£179	£180	£184	£190	£196	£202	£207	£214	£220	£221	£216	£204	£70
Emergency Dept. Care	Survivors	£7	£7	£6	£8	£6	£7	£6	£7	£7	£7	£8	£7	£7
	Decedents	£14	£13	£15	£15	£17	£20	£21	£25	£28	£32	£41	£46	£65
Primary Care	Survivors	£101	£48	£65	£95	£65	£91	£74	£77	£89	£67	£97	£55	£112
	Decedents	£106	£75	£91	£103	£91	£101	£95	£98	£102	£91	£100	£71	£45
Outpatient Care	Survivors	£23	£21	£22	£23	£23	£22	£21	£22	£20	£22	£21	£21	£22
	Decedents	£35	£33	£31	£34	£36	£32	£35	£35	£32	£29	£26	£19	£11

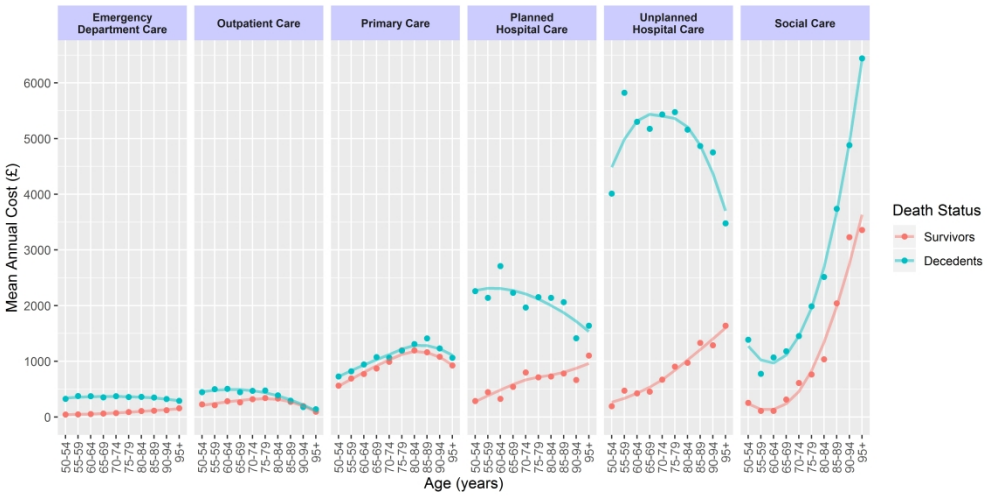

Emergency Department Care
Outpatient Care
Primary Care
Planned Hospital Care
Unplanned Hospital Care
Social Care
Mean Annual Cost (£)
0
1000
2000
3000
4000
5000
6000
50-54
55-59
60-64
65-69
70-74
75-79
80-84
85-89
90-94
95+
Age (years)
Death Status
Survivors
Decedents

Figure 1

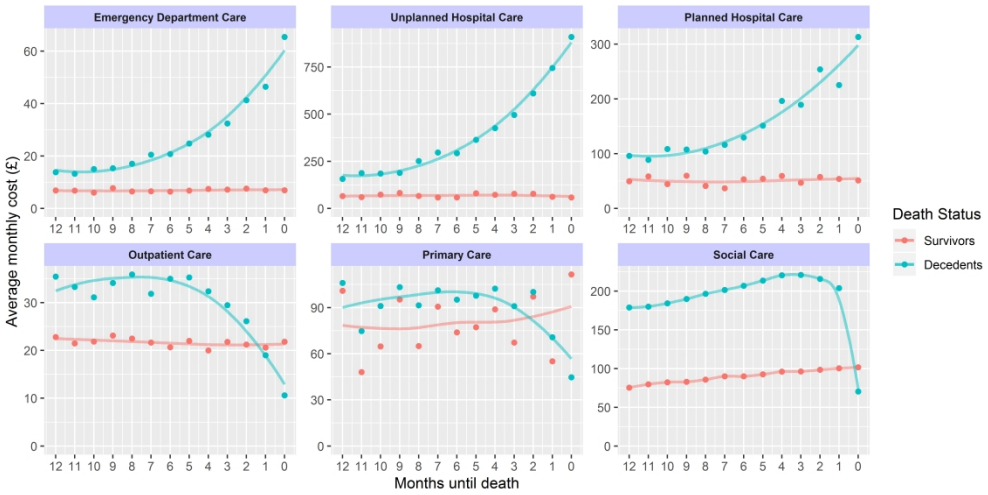

Emergency Department Care
Unplanned Hospital Care
Planned Hospital Care
Outpatient Care
Primary Care
Social Care
Average monthly cost (£)
Months until death
Death Status
Survivors
Decedents

Figure 2