



## The impact of having a carer on adult health and social care utilisation across five settings of care: A matched cohort study

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### ABSTRACT

**Introduction:** An estimated 6.8 million people are (informal) carers in the UK. The economic value of annual carer contributions is an estimated .132bn. Reliance on carers appears to be increasing. There is mixed evidence on whether carers are substitutes for formal care.

This study investigated the association between having a carer and service use patterns across five care settings when compared to a matched cohort without a carer.

**Materials and Methods:** A matched case-control group analysis using person-level data in Barking and Dagenham (B&D), a London borough in the U.K., to assess the impact of having a carer in terms of the differences in cost-weighted utilisation relative to a matched control group.

**Results:** In 2016/17, for adult residents of B&D, having a carer ( $n = 1,295$ ) was associated with 27% increased cost-weighted utilisation (mean difference of £2,662, CI £1,595, £3,729,  $p < 0.001$ ) compared to a matched cohort without a carer. 39% of the cost difference was social care.

**Conclusions:** Findings suggest additional service use induced by carers may dominate any substitution effect. Having a carer may be a key element in enabling access to services. As such, there may be wider inequalities in service access for people without a carer. For an ageing society with projections suggesting there will be more people without carers in the future, these inequalities need to be addressed.

### Introduction

Globally, an increasing number of people with long-term conditions and social care issues are managed at home with support from carers. Across the UK today, an estimated 6.8 million people are carers, supporting friends and family who are older, disabled or seriously ill [1]. These carers are unpaid and often described as “lay”, “informal” or “family” carers [2]. In England, the economic value of the contribution made by carers is an estimated £132 billion a year [1]. This is calculated using national survey data on hours of care provided [3] and estimates of unit costs of replacement homecare. Reliance on carers appears to be increasing, with reductions in council budgets resulting in fewer people getting access to formal support [4].

The literature on the impact of carers on the care recipient’s health and social care utilisation is mixed. On the one hand, the estimated economic value of carer contributions assumes care substitution, by having a carer people require fewer hours of paid homecare [1]. On the other hand, having a carer could increase service utilisation as the

individual has an advocate who can facilitate access to services, transport them to appointments, overcome denial that more care is needed and ensure full care needs are met. Research in Canada found both for end-of-life patients: having a carer reduced the need for home-based care services, but increased utilisation of physician and nurse visits [5]. A review of informal care across nine European countries found care substitution for unskilled tasks [6]. Research to date highlights the complexity associated with substitution of care between formal and informal care services [7, 8] and the different roles the different care types provide [9]. Regardless, there is alignment that a growing ageing population alongside reductions in funding for state-funded social care will lead to a greater reliance on informal care [10].

The NHS in England has a policy commitment to improve identification of carers and strengthen support for them, in recognition of the impact being a carer can have on carer’s health and so they can maintain their caregiving role [11]. This has led to documentation of whether or not someone is a carer, has a carer or both in primary care health records using Read Codes [12]. Formal recognition of having a carer can be

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required for the carer to access benefits and respite support.

This study aimed to understand if people with a carer have different levels of service use across five settings of health and social care when compared to those who do not have a carer but have matched individual characteristics.

## Materials and methods

A matched case-control group analysis using person-level data to assess the impact of having a carer in terms of the differences in the cost of service use across five settings of care relative to a matched control group.

### Dataset

A subset of a linked dataset in Barking and Dagenham (B&D) was used. B&D is a densely populated urban borough in London, England, with 210,700 residents, high levels of deprivation and ethnic diversity. The primary outcome measures were total cost and setting-level costs for hospital, primary care, community care, mental health and social care.

The following types of care were included: hospital services (accident and emergency (A&E) attendances, elective and non-elective inpatient stays and outpatient appointments); primary care contacts; prescriptions; community care contacts (home visits, appointments with community teams including nurses, pharmacists and allied health professionals); mental health services (inpatient stays and outpatient appointments); and social care (weekly care packages which included costs for crisis intervention, home care, supported living placements, residential and nursing home placements). The total cost was estimated from activity data using a combination of national tariffs (for hospital services), unit costs (for primary, community and mental health), and weekly commissioned spend (for social care). Data was not available on self-funded social care, costs for equipment, transport and home adaptation. The total cost was calculated by aggregating individual costs across the five settings of care.

The exposure variable was taken from the primary care records using Read Codes that identify if someone has a carer (918F). Carers may be family members, neighbours or friends. The nature of support or number of hours was not available. Costs were not assigned to carers' activities.

### Cohort

Adult residents of B&D between 1st April 2016 and 31st March 2017 were the base cohort for the analysis. Those who died or moved out of B&D before the 1st April 2017 were excluded from the cohort as they had less than 12 months of activity data, and known increase in healthcare utilisation at the end of life [13] could bias results. Of the remaining 114,393 adults, the following individuals were excluded:

- **Those who had a carer and were a carer ( $n = 101$ )** as the nature of their care needs could be different given their ability to be a carer. Spouse carers, a growing cohort [14], were therefore excluded.
- **Those who had no carer but were a carer ( $n = 861$ )** as the known associations between being a carer and declined health status [15] would impact interpretation of results if they were included as controls.
- **Individuals who lived in households with an occupancy of 11 or more ( $n = 1115$ , which included 33 individuals who had a carer)** were assumed to be in a care home setting and therefore excluded from both the treatment group and control group as their health and social care use are likely to be different from those residing in their own home [16].

The remaining dataset had 112,316 adults, of which 1295 were documented as having a carer. Table 1 provides a summary of the characteristics of the 1295 that had a carer.

**Table 1**

Summary characteristics of the cohort of residents of Barking and Dagenham in 2016/17 who had a carer ( $n = 1295$ ).

- 47% 75 years or older with 20% over 85 years
- 55% Female, 45% Male
- 38% obese or morbidly obese
- 61% non-smokers
- 68% had 2 or more of 16 long term conditions, 19% had 4 or more
- The most prevalent conditions were Hypertension (46%), Learning disability (26%), Diabetes (21%)
- 53% in receipt of housing benefit
- 34% lived alone, 55% lived in a 2–4 person household

### Matching

People with a carer differ from those who do not (e.g., those with carers tend to be older and have a greater degree of morbidity), such that the mean costs of the two groups are not directly comparable (see Table 2). In this study, we sought to create two comparable groups that were identical with respect to all observed characteristics, except the exposure to a carer.

Matching is a long-standing approach to assess treatment effects in observational research [17]. It involves balancing the distribution of covariates in the exposed and unexposed groups in order to control for any systematic differences between these groups and provide unbiased estimates of treatment effect. It assumes there is no unmeasured confounders that are associated with the chances of having a carer and health care utilisation. In this study, the exposure or “treatment” is “having a carer”, and the primary outcome of interest is the cost of health and social care service use overall and for five settings of care. We evaluated the effect of having a carer among those with and without a carer (the average treatment effect (ATE)).

Nearest neighbour matching with a minimum of one match was used for the analysis. The nearest neighbour was calculated using Mahalanobis distance, in which the weights are based on the inverse of the covariates' variance-covariance matrix. We matched people on age, gender, ethnicity, deprivation, BMI category, smoking status, the number of and prevalence of 16 conditions, housing tenure, benefits received and housing occupancy. This created a matched cohort of 2590, with 1295 that had a carer and 1295 that did not. We conducted robustness checks using alternative matching approaches, including: 1) exact matching on all confounders listed above, 2) a combination of nearest neighbour matching with exact matching on age, and 3) propensity score matching.

All data processing, matching and analysis were conducted using Stata version 15.1.

## Results

Of the 112,316 individuals included in the analysis, 1295 people had

**Table 2**

Mean costs for each setting of care for those who have a carer compared with the full cohort of people who did not have a carer in Barking and Dagenham in 2016/17.

	Have a carer $n = 1295$		Do not have a carer $n = 111,021$		T-test result of the difference in means
	Mean (£)	Standard deviation	Mean (£)	Standard deviation	
Total costs	12,680	20,797	1415	5648	$p = 0.00$
Hospital	1606	3486	542	1680	$p = 0.00$
Primary care	1014	1292	274	501	$p = 0.00$
Community	2969	9416	334	3254	$p = 0.00$
Mental health	2499	11,939	142	2644	$p = 0.00$
Social care	4593	11,155	123	1799	$p = 0.00$

a carer and 111,021 people did not. After matching, the balance between the exposed and unexposed group improved across all variables, with standardised differences brought within the threshold for meaningful balance (Fig. 1). Standardised differences are calculated by the difference in means of each covariate between those with a carer ( $X_t$ ) and those without ( $X_c$ ) divided by the standard deviation in the full matched cohort (SD):  $(X_t - X_c)/SD$ . A standard difference of more than 10 has been denoted by some as indicating meaningful imbalance, smaller values indicate better matches. Some residual imbalance remained for age and ethnicity.

The ATE was computed to calculate the difference in costs between exposed and unexposed matched groups. Table 3 shows the results for the mean difference in total costs and the mean difference in costs by setting of care.

The mean total cost of service use for those without a carer was £10,018 (£987 hospital, £823 primary care, £2608 community care, £2043 mental health and £3557 social care). Having a carer was associated with 27% increased total cost of service use (mean difference of £2662, CI £1595 - £3729,  $p < 0.001$ ) when compared with those without a carer. The increase in cost was found across all five care settings. Social care was the largest contributor, accounting for £1036 (39%) of the overall cost difference. Mental health cost differences were not statistically significant.

Robustness checks (Fig. 2) reported similar differences in costs between people with a carer and those without, suggesting that the estimated effect of having a carer is relatively robust to the choice of confounding adjustment approach.

**Table 3**

The differences in mean cost by setting for people with a carer vs those without a carer (controls), matched on age, gender, ethnicity, deprivation, BMI category, smoking status, the number of LTCs, the prevalence of 16 conditions, housing tenure, benefits received and housing occupancy.

	Mean ATE of having a carer, £	% of total cost	95% CI		<i>p</i>
Total cost	2662	100%	1595	3729	0.00
Hospital	619	23.3%	75	1164	0.03
Primary care	191	7.1%	108	274	0.00
Community	360	13.5%	134	587	0.00
Mental health	455	17.1%	-30	941	0.07
Social care	1036	39.0%	474	1598	0.00

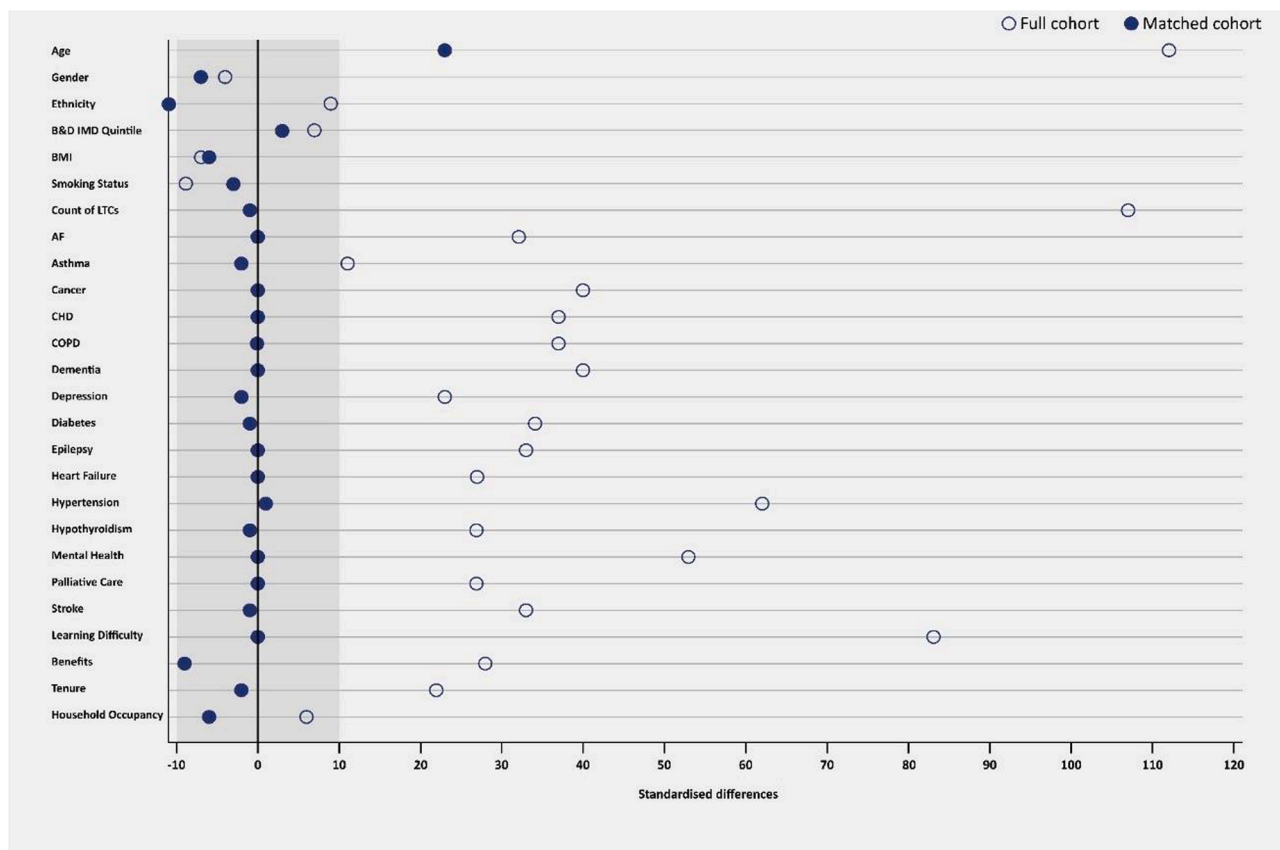
## Discussion

### Summary of results

For the adult residents of B&D between 1st April 2016 and 31st March 2017, health and care costs were £2662 (27%) higher for people registered in their primary care records to have a carer compared to a comparable group who were not registered as having a carer. Social care accounted for much of this difference (39%).

### Comparison with the literature

There are conflicting perspectives in the literature as to whether having a carer increases or reduces an individual's health and social care



**Fig. 1.** The standardised differences for key variables for the full dataset and for the matched cohort. Note: Values within the grey shaded area (between -10 and 10) denote meaningful balance between the cases and controls. 0: no difference between exposed and unexposed groups, negative values represent variables for which the effect of the difference between the exposed and the unexposed is reversed.

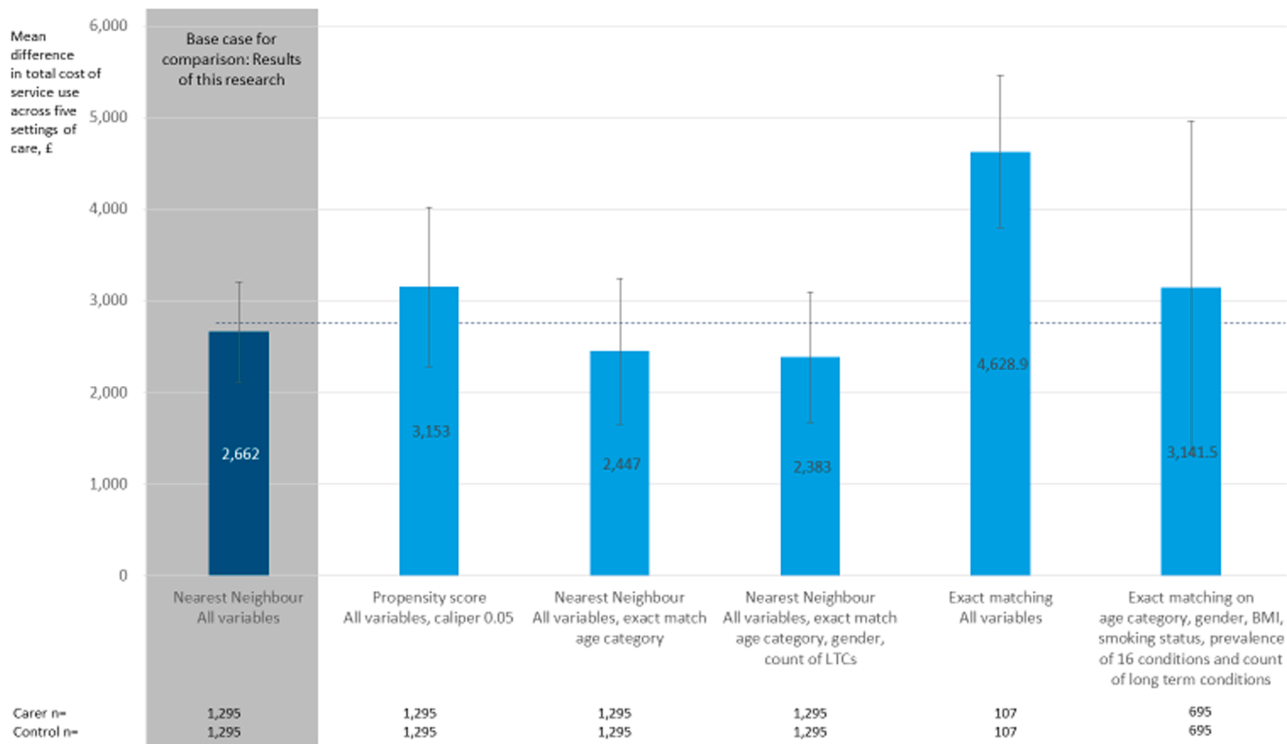


Fig. 2. Output of the robustness checks comparing the mean difference in total costs for people with a carer compared to those without for different matching scenarios.

service utilisation. The literature on the different methods to cost the contribution of informal carers [18] assumes carers provide care substitution with the presence of a carer replacing the need for formal paid care. Our findings, that people without carers have lower costs across all settings, suggest that if there is care substitution from having a carer, those without not only do not have the care provided by the informal carer but they also have lower use of other services, potentially widening health inequalities.

The literature provides possible explanations for the increased costs observed for the cared for cohort. Firstly, a caregiver acting as an advocate for a patient can increase utilisation of some types of care, for instance by facilitating visits to hospital emergency departments or helping to overcome denial that more care is needed [19]. Some studies have found interdependent and potentially conflicting patient and caregiver preferences with regards to service access, with carers more likely to proactively seek help when the care recipient would not, or to preference longer active treatment than their care recipient [20, 21]. In addition, individuals in the Newcastle 85+ study reported high health and functional ability despite significant levels of disease and impairment [22]. This may lead to different health seeking behaviour for individuals without a carer and may explain the increased service use for those with a carer.

Having a carer has been shown to improve the quality of life for the care recipient [19]. Higher access to services and having an advocate may contribute to that quality of life. The increased service use observed for the cared for cohort needs to be assessed in the context of the wider health and wellbeing outcomes that having a carer provides.

With regards to mental health, the increase in cost was not significant for people with a carer. This may reflect the different nature of mental health service provision, carers of people with acute mental health needs may not be registered in primary care records or it may be reflective of the ongoing impact of stigma of mental illnesses in determining the health-seeking behaviour of the care recipient [23] and their carer.

### Strengths and limitations

A strength of the study was the breadth of services included (five settings of care), in particular community services, mental health and social care. This allowed for a broader picture of the impact of carers on health and social care costs compared to previous studies.

By using matching, we have sought to minimise any systematic differences in observed confounders between individuals exposed and unexposed to carers. In addition, unlike regression modelling, these matching approaches make weaker parametric assumptions [24] and are expected to provide more robust estimates about the effect of carers on health and social care costs.

There are several limitations to note. Firstly, the analysis identified people who had carers from primary care records. This is likely to underestimate the number of people with carers. Less than 1% were identified in the dataset. In B&D, 8.7% of the adult population reported being informal carers in the 2011 census [25] and 1 in 10 of the adult population were reported to be carers in April 2019 [26]. One of the reasons for the low levels of carers identified through primary care is the uncertainty around the definition of the term “carer”. Extensive literature shows many carers do not identify themselves as a carer and are protective of their relationships with the person they care for, seeing caring as part of their role as a spouse, parent or child and not wanting to formalise or label the care they provide [27]. The risk to our analysis of low carer numbers is that the unexposed cases may contain people who have carers that are not formally registered with primary care, misrepresenting them as controls.

It was not possible to confirm whether or not the recording of having a carer was missing at random and as such the extent to which it could introduce selection bias. In addition, those who had been identified as having a carer may have a higher level of need such that having a carer is another marker of increased acuity. As such, there may be people who have a carer who have not been identified in our dataset who have lower levels of service use. If this is the case, the research findings may overestimate the effect of having a carer on service use as it may be higher

levels of need rather than the presence of a carer that are associated with the increased service use. Whilst the matching process included variables that attempt to control for the need/health status of individuals with carers they might not fully capture the full care needs. If need is not fully captured by the included covariates in the model, the carer variable may act as a proxy for need. Further investigation with more detailed information on individual care needs and the nature of care given by the carer would be necessary to investigate this further.

The role of the carer and the nature of the caring activities can vary widely. The literature indicates several dimensions of the role of the carer and the nature of the caring activities that are important markers of variation; these include the prime reasons for carer support, the different roles carers provide, the number of hours the carer provides support, the length of time the individual has had a carer, whether the carer lived with the care recipient and the characteristics of the carer (age, gender, education and employment status). The “Personal Social Services Survey of Adult Carers” confirmed that each of these dimensions can vary greatly for carers in the U.K [28]. The dataset we used did not have access to these dimensions so it could not be adjusted for them.

Information on other forms of voluntary services or on services individuals may have paid for privately was not available; this would have been particularly important for the control group: their reduced service use could have been due to receiving other forms of care not accounted for in the dataset. However, the deprivation profile and low average earnings of households in B&D suggest that the proportion of people able to self-fund their care is likely to be very low [29].

Further limitations include lack of longitudinal analysis, which could have provided a greater understanding of whether the differences in service utilisation between people with a carer and those without changed over time and the sequencing of service use. Furthermore, while we have not identified any major factors that could be an important predictor of health and social care costs that have not been measured, there may still be unobserved confounding.

### Implications

In the UK, much of the discourse on the role of carers rests on the economic assumption that carers are a substitute for formal care, with an hour of their time being directly comparable to an hour of a paid carer [1]. As such, policy priorities are to identify carers, provide them with information, and support them to continue their care giving role by addressing their own health and wellbeing needs [30]. With a growing ageing population, it is anticipated that the need for care will continue to grow and supporting carers to continue to deliver caregiving will reduce the burden on the care system. The findings of this research challenge some of these assumptions as individuals with carers were found to have higher health and social care costs than those without. This raises questions on the relationship between informal care and the formal care system. The project did not attempt to conduct a full impact assessment of carers but rather to understand the impact that having a carer has on an individual’s health and social care utilisation. The increased costs across all settings of care suggest that carers do not provide care substitution of the tasks and activities completed by the health and social care system or, or perhaps, that additional service use induced by the carer may dominate any substitution effect. If there was care substitution, we may have expected to see reduced service use in social care, and potentially community care settings, for people with a carer where some of the tasks can be completed by an unskilled workforce. The informal carers may be filling unmet needs, such as coordinating care, advocating for the care recipient, providing emotional and social support, all of which may have a positive impact on the quality of life of the person being cared for.

There is an opportunity to reflect on the relationship between carers and the formal care system and identify interventions that could support more care substitution. This may include providing bespoke training and

education and seeing carers as an extension of the care workforce. Over the past decade, patient education for self-care has become a core function of the NHS, recognising that an individual spends more time caring for themselves than interacting with health and care professionals. The same logic may be applied to carers. However, carer education is largely delivered by the voluntary sector and as yet has not become an explicit role of the NHS, despite the potential for impact.

Health inequalities are a growing challenge for all societies and are of global concern, although the magnitude of the problem varies across countries. The findings of this work suggest people without carers may be experiencing inequitable access to services. This should be investigated further.

### Conclusions

This research has shown important new light onto the health and social care utilisation levels of people with carers. It suggests that such support may be a key element in enabling individuals to access services and, as such, there may be wider inequalities in access to services for people without a carer. Globally our society is ageing. Projections suggest that there will be more people without carers in the future, these inequalities need to be addressed.

Further research would be beneficial to understand differences in total cost of service use in more depth; including different categorisations of people who have a carer, the scale and nature of care received and longitudinal patterns. Access to health and wellbeing outcomes would be beneficial. This would facilitate a fuller assessment of the net impact of informal care on an individual’s health and wellbeing.

### CRediT author statement

**Jenny Shand:** Conceptualization; Data curation; Formal analysis; Methodology; Writing - Original draft preparation

**Manuel Gomes:** Methodology; Supervision; Writing - review & editing.

**Steve Morris:** Methodology; Supervision; Writing - review & editing.

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### Ethics

This study meets national guidelines set out by the Research Ethics Service for the NHS in UK. No further ethics approval was required. (<http://www.hra-decisiontools.org.uk/ethics/resultN2.html>).

### Data sharing

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. Further information about the dataset is available in the supplementary material.

### CRediT authorship contribution statement

**J. Shand:** Conceptualization, Data curation, Formal analysis, Methodology, Writing – original draft. **M. Gomes:** Methodology, Supervision, Writing – review & editing. **S. Morris:** Methodology, Supervision, Writing – review & editing.

## Declaration of interests

We declare no competing interests.

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## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.healthpol.2022.104705](https://doi.org/10.1016/j.healthpol.2022.104705).

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