RESEARCH PAPER

Factors associated with accessing long-term adult social care in people aged 75 and over: a retrospective cohort study

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Abstract

Background: An ageing population and limited resources have put strain on state provision of adult social care (ASC) in England. With social care needs predicted to double over the next 20 years, there is a need for new approaches to inform service planning and development, including through predictive models of demand.
Objective: Describe risk factors for long-term ASC in two inner London boroughs and develop a risk prediction model for long-term ASC.
Methods: Pseudonymised person-level data from an integrated care dataset were analysed. We used multivariable logistic regression to model associations of demographic factors, and baseline aspects of health status and health service use, with accessing long-term ASC over 12 months.
Results: The cohort comprised 13,394 residents, aged ≥75 years with no prior history of ASC at baseline. Of these, 1.7% became ASC clients over 12 months. Residents were more likely to access ASC if they were older or living in areas with high socioeconomic deprivation. Those with preexisting mental health or neurological conditions, or more intense prior health service use during the baseline period, were also more likely to access ASC. A prognostic model derived from risk factors had limited predictive power.
Conclusions: Our findings reinforce evidence on known risk factors for residents aged 75 or over, yet even with linked routinely collected health and social care data, it was not possible to make accurate predictions of long-term ASC use for individuals. We propose that a paradigm shift towards more relational, personalised approaches, is needed.

Keywords: Older adults, risk prediction modelling, routinely collected data, frailty, adult social care

Key Points

- Rising cost of ASC and limited resources call for better ways to inform service planning and development
- Predictive models to anticipate long-term ASC have been proposed as an approach but lacked adequate routine data
- We used integrated administrative data to test this approach and identified groups at risk, but these are largely already known
- The development of a prognostic score was limited by lack of key predictors, rarity of outcome and complexity of social care
- We propose a paradigm shift and an alternative approach, to identify and support need early on at an individual level

Introduction

The rise in demand for healthcare by an ageing population together with budgetary constraints has put great pressure on the availability of adult social care (ASC) [1–4]. In response, healthcare organisations and researchers have developed practices of care and support, focusing on prolonging functional independence [5]. This is done through exploring possible risk factors associated with unplanned outcomes [6], typically readmissions to hospital [7–10] or through the use of predictive models to forecast outcomes. Predictive models are widely used by health care providers in the UK and US due to their potential to inform early interventions. However, equivalent models for predicting new onset of long-term ASC, defined as need for help with tasks of daily living in the community or in care homes, are rare, particularly those using administrative data [5].

Studies exploring ASC in those with no prior social care need [4] often rely on self-reported functional independence. For instance, by combining risk factors into a validated instrument for screening older adults, Goodlin et al. were able to identify independent older adults at high risk for needing long-term care in 12 months [5]. Although this study used a wide range of data, it was based on self-reported need for long-term care (NLTC). Similarly, Covinsky et al. [2] predicted adults' ability to carry out activities of daily living (ADL) such as bathing, dressing and eating without the help of another person, by asking participants if they received help with ADLs.

Unlike Goodlin et al. [5] and Covinsky et al. [2], Bardsley et al. [11] relied on linked health and social care data, including prior use of social care, to predict use of intensive social care within 12 months. All three models reported low to moderate positive predictive values and low sensitivities. The authors attributed this to the rarity of the predicted outcome, and suboptimal quality and completeness of routine data. The data used in these models were obtained and linked from consenting parties in a bespoke fashion to prove the concept of predictive case finding in social care.

A model that could predict which individuals, previously unknown to local authorities, might access a package of care arranged through these local authorities in the near future would be of considerable benefit in planning. Such a model, by necessity, could not include prior use of social care as a predictor. This study extends the literature on ASC in two ways. Firstly, we explore factors associated with accessing long-term ASC among older adults not known to receive social care in a defined period, using routinely available combined health and social care data; then we build a predictive risk model to forecast future use of long-term ASC arranged by the state. The intention is that the resulting model could be used prospectively by local authorities to stratify residents and implement prevention measures such as falls clinics, adaptations around the home and informal carer support. Receiving care in the community or moving into a care home setting may be a positive choice for the person or an unavoidable necessity. Either way, costs arise to the local authority; hence, models that can help proactively plan for state arranged ASC would be useful.

Methods

This retrospective cohort study was conducted using the Northwest London (NWL) Discover Database, an integrated individual-level dataset covering 2.3 million residents of NWL currently registered with a general practitioner (GP). This is a de-identified research data set derived from clinical electronic health records. It comprises linked data on primary, secondary, and tertiary care, community and mental health care, emergency departments and social care [12]. Primary care data are sourced from GP electronic record systems, whereas secondary care data are sourced from a secondary uses service dataset [13]. Administrative data derived from organisation and delivery of ASC by NWL local authorities are also included in this data set. This is a standard common dataset recording each package of care arranged by local authorities, and collated in ASC datasets nationally (see Supplementary Material for more detail). The study period was 1 January 2018–31 December 2019 and was divided into two periods: the baseline period, 1 January 2018 –31 December 2018 and the follow-up period, 1 January 2019–31 December 2019.

Participants

Participants were eligible for inclusion if they were (i) registered with a GP and resident in either one of two NWL inner boroughs; (ii) aged 75 or over at the start of the follow-up period; (iii) not known to the local authority to have accessed long-term or short-term ASC in the 6-year period to 31 December 2018 (the whole period for which ASC records were available).

Outcome variable

The primary outcome was accessing long-term ASC within the 12-month follow-up period, defined as provision of at least one package of long-term ASC. We defined long-term ASC as ongoing care provided to clients, which may vary from lower intensity support such as receipt of home care visits or direct payments to support them, to higher intensity support such as admission to a care home, regardless of duration (Appendix 1). We did not include reenablement. We included all long-term ASC arranged through the local authority. This included care for clients receiving long-term support wholly or part funded by the local authority, or arranged by the local authority where the client is paying for the full direct cost of their care and support. Local data indicate that the latter constitutes ∼5–10% of participants at any one time. We also included care wholly or partly funded by the National Health Service (NHS), estimated to be ∼12% of the total ASC expenditure [14]. No data were available for clients who self-funded and were not known to the local authority, for example when people arranged social care for themselves or their family through a private provider.

Sociodemographic and health variables

Covariates (Appendix 2) included: gender, age group, ethnicity, socioeconomic status based on the 2015 index of multiple deprivation (IMD) decile [15] and household structure (lives alone, does not live alone, unknown). Diagnosed long-term conditions (LTCs) were grouped into disability, autoimmune/inflammatory, cardiovascular, respiratory, malignancy, endocrine, neurological, mental health and end-of-life care (Appendix 3). Variables measuring health service use during the baseline period included: emergency admissions, elective admissions (day and regular), unplanned accident and emergency attendances (i.e. A&E arrivals by ambulance), average episodes per spell, number of active outpatient specialties and X-ray investigations. Counts of each variable were grouped into categories.

Statistical analysis

The unit of observation was an individual. Residents with incomplete sex, age, ethnicity or IMD records were excluded. We calculated distributions of the outcome conditional on each covariate. Comparisons in categorical variables between the two groups are conducted using χ^2 tests. Variables 'Autoimmune diseases', 'End-of-life care' and 'regular electives' (referring to recurring elective admission to hospital) are not included in the analysis because counts were below 5 and therefore too low to be published through NWL Discover information governance requirements. Such low frequency events are also unlikely to impact on the findings of this study. We also conducted a geographic analysis to map NWL middle-layer super output areas (MSOAs) showing coverage of those that received long-term ASC (Appendix 4).

A multivariable logistic regression was fitted with the outcome variable and covariates as aforementioned. A purposeful model selection approach was taken, considering factors likely to be associated with the exposure and outcome. This approach was based on previous studies [4–6, 11, 16, 17], clinical and local council input. We assessed model fit using goodness-of-fit tests and tested for multicollinearity. Estimated odds ratios (ORs) with 95% confidence intervals (CIs) and associated P-values are reported.

We fitted models to identify those at high risk of accessing long-term ASC within 12 months. We randomly split the dataset into training (70%) and test (30%) sets. Due to class imbalance, we resampled the training dataset using four approaches: up-sampling, randomly over-sampling the minority class; down-sampling, randomly under-sampling the majority class; synthetic minority over-sampling technique (SMOTE), a combination of up- and down-sampling [18]; and random over-sampling examples (ROSE), a bootstrap-based technique generating synthetic examples from a conditional density estimate of the two classes [19]. These approaches minimise impact of unbalanced data on performance of the algorithms [20].

As in other well-known risk prediction models, such as the PARR-30 model for predicting hospital readmission,

[21] residents who died during follow-up were included in the models. This reflects the intended application of the model in practice. Performance of models was assessed using sensitivity, specificity and area under the receiver operating characteristic curve (AUC). Analyses were carried out using R (version 4.0.2).
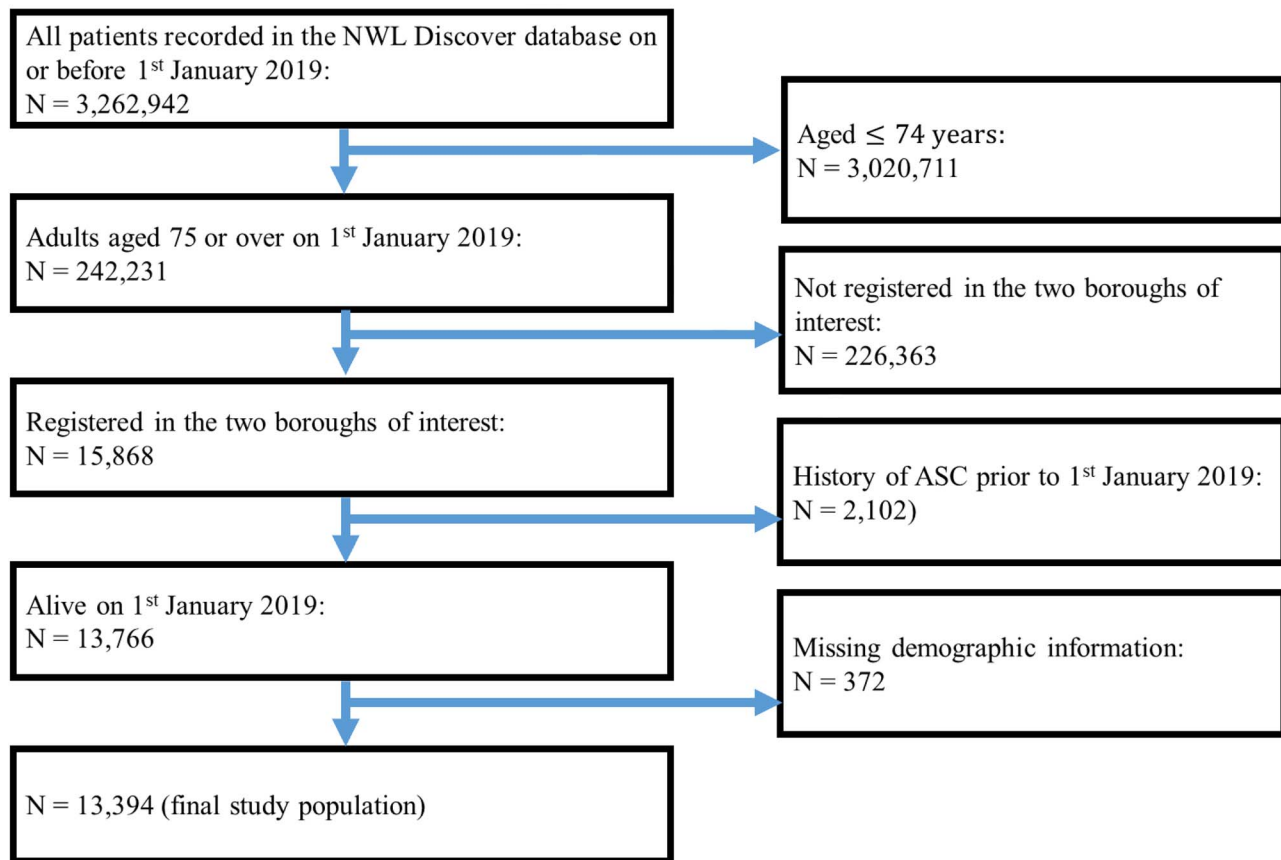
Results

About 13,766 residents met the inclusion criteria, and after excluding 372 with missing demographic information, 13,394 were included in the analysis (Figure 1). Of these, 7,322 (54.7%) were female, and 9,678 (72.3%) were White (Table 1). During the 12-month follow-up, 223 (1.7%) became long-term ASC clients for at least part of the period. Of these, 62.3% were female compared with 54.5% among those not receiving long-term ASC (P = 0.024). Those receiving ASC were more likely to be older (39.5% vs. 22.6%, P < 0.001). Differences in ethnicity between the two groups were not significant (P = 0.22). A higher proportion of those receiving ASC live in the most deprived areas (37.2%) compared with those not receiving ASC (23.7%). Household structure was documented more often among those receiving ASC, and when it was, more residents were recorded as living alone among those receiving ASC compared with those not (P < 0.001). About 74% of the cohort had at least one LTC, with cardiovascular disease as the most common LTC (62.2%). Of all LTCs, significant differences were observed in endocrine diseases, neurological and mental health conditions with the highest proportions in the ASC group for all three conditions. There were significant differences in mortality rates between those who received ASC and those who did not (9% vs 3.3%, P < 0.001).

Health service use at baseline

Participants newly accessing long-term ASC arranged by local authorities had, in the baseline period, been admitted to hospital as an emergency more frequently, had more inpatient episodes per hospital admission, had more outpatient appointments, more arrivals at A&E by ambulance and more X-ray investigations during hospital admissions, than those who did not receive ASC (Table 2). There was no difference in the number of day elective admissions during baseline between those who did and did not go on to receive long-term ASC.

Geographic variation

Almost half of the 45 MSOAs across the two boroughs had fewer than 5 residents accessing ASC during follow-up. These results were not included in the geographic analysis to comply with information governance requirements. The Spearman's rank correlation of average socioeconomic deprivation and percentage of residents receiving ASC was 0.59, suggesting some evidence of higher need for state-arranged ASC in areas of greater deprivation.

Figure 1. Flow chart displaying study inclusion and exclusion criteria with numbers of participants included at each stage.

Multivariable logistic regression results

After adjustment, participants were more likely to receive new long-term ASC if they were older, with those aged 85+ having odds twice as high as those aged between 75 and 80 (OR 2.17, 95% CI 1.55–3.04, $P < 0.001$) (Appendix 5) and Figure 2. Those living in areas with higher socioeconomic deprivation were also more likely to receive long-term ASC, with threefold difference in odds between the most and least deprived areas (OR 0.37, 95% CI 0.23–0.56, $P < 0.001$). Finally, participants with a preexisting mental health (OR 1.76, 95% CI 1.27–2.40, $P < 0.001$) or a neurological (OR 2.11, 95% CI 1.41–3.06, $P < 0.001$) condition were more likely to receive ASC. Associations between health service use at baseline and long-term ASC persisted in the multivariable analysis.

Predicting risk of accessing long-term ASC arranged by local authorities

The logistic regression model trained with imbalanced data was unable to correctly classify any of those accessing long-term ASC, corresponding with a sensitivity of 0 and specificity of 1 (Table 3). The class imbalance meant that despite this, the model had the highest overall accuracy. Models trained with the resampled data were able to correctly classify at least some of those receiving ASC, with the ROSE strategy giving the highest sensitivity.

Discussion

Unlike previous combined health and social care models, which relied on bespoke data, we looked at the potential use of routine data for case finding and potential preventive action. We examined factors associated with new use of long-term ASC, among residents aged 75+ years with no history of having received care and support in a defined period, and the possibility of making individual-level predictions on future ASC use. Of the 13,394 participants, 1.7% became long-term ASC clients for at least part of the 12-month follow-up period. Residents were more likely to receive ASC if they were older, aged 85+, living in areas with higher socioeconomic deprivation or had preexisting mental health or neurological conditions. Residents with two or more emergency admissions, or three or more active outpatient specialities during the baseline period were also more likely to receive long-term ASC.

None of these findings are surprising. Age (older than 80) is a key independent predictor of loss of functional independence [2]. Similarly, socioeconomic deprivation not only makes self-funding care less likely but is also in itself a predictor of poor health [22]. Furthermore, we found that residents with two or more emergency admissions during the baseline period, and those with three or more active outpatient specialties were more likely to receive ASC. Although we did not specifically investigate frailty, a higher

Table 1. Socio-demographic characteristics and health status of participants stratified by those who newly received long-term ASC arranged by the two local authorities in the 12-month follow-up period and those who did not

	Long-term ASC		Combined	x^2 P
	Yes =223	No = 13,171	n = 13,394	
Sex				
Male	84 (37.7%)	5,988 (45.5%)	6,072 (45.3%)	P = 0.024
Female	139 (62.3%)	7,183 (54.5%)	7,322 (54.7%)	
Age, yr				
75–79	69 (30.9%)	6,127 (46.5%)	6,196 (46.3%)	P < 0.001
80–84	66 (29.6%)	4,067 (30.9%)	4,133 (30.9%)	
85+	88 (39.5%)	2,977 (22.6%)	3,065 (22.9%)	
Ethnicity Group				
White	150 (67.3%)	9,528 (72.3%)	9,678 (72.3%)	P = 0.22
Mixed/Other Ethnic	31 (13.9%)	1,745 (13.2%)	1,776 (13.3%)	
Asian or Asian British	20 (9.0%)	1,009 (7.7%)	1,029 (7.7%)	
Black or Black British	22 (9.9%)	889 (6.7%)	911 (6.8%)	
IMD quintiles				
1 (most deprived)	83 (37.2%)	3,121 (23.7%)	3,204 (23.9%)	P < 0.001
2	60 (26.9%)	3,238 (24.6%)	3,298 (24.6%)	
3	50 (22.4%)	3,386 (25.7%)	3,436 (25.7%)	
4–5 (least deprived)	30 (13.5%)	3,426 (26.0%)	3,456 (25.8%)	
Household structure				
Does not live alone	9 (4.0%)	436 (3.3%)	445 (3.3%)	P < 0.001
Lives alone	62 (27.8%)	1,904 (14.5%)	1,966 (14.7%)	
Unknown	152 (68.2%)	10,831 (82.2%)	10,983 (82.0%)	
Status at end of follow-up				
Alive	203 (91.0%)	12,741 (96.7%)	12,944 (96.6%)	P < 0.001
Dead	20 (9.0%)	430 (3.3%)	450 (3.4%)	
LTCs				
Disabilities				
No	154 (69.1%)	9,467 (71.9%)	9,621 (71.8%)	P = 0.40
Yes	69 (30.9%)	3,704 (28.1%)	3,773 (28.2%)	
Cardiovascular diseases				
No	83 (37.2%)	4,975 (37.8%)	5,058 (37.8%)	P = 0.92
Yes	140 (62.8%)	8,196 (62.2%)	8,336 (62.2%)	
Respiratory diseases				
No	188 (84.3%)	11,573 (87.9%)	11,761 (87.8%)	P = 0.13
Yes	35 (15.7%)	1,598 (12.1%)	1,633 (12.2%)	
Malignancy diseases				
No	208 (93.3%)	11,836 (89.9%)	12,044 (89.9%)	P = 0.12
Yes	15 (6.7%)	1,335 (10.1%)	1,350 (10.1%)	
Endocrine diseases				
No	200 (89.7%)	12,300 (93.4%)	12,500 (93.3%)	P = 0.04
Yes	23 (10.3%)	871 (6.6%)	894 (6.7%)	
Neurological disease				
No	189 (84.8%)	12,375 (94.0%)	12,564 (93.8%)	P < 0.001
Yes	34 (15.2%)	796 (6.0%)	830 (6.2%)	
Mental health condition				
No	165 (74.0%)	11,173 (84.8%)	11,338 (84.6%)	P < 0.001
Yes	58 (26.0%)	1,998 (15.2%)	2,056 (15.4%)	

number of those emergency admissions and outpatient appointments could relate to an individual's frailty severity [23]. The association between chronic conditions and accessing long-term ASC was strong and significant, regardless of demographic characteristics and health service use. Neurological and mental health conditions were found to increase risk, with those with a neurological condition twice as likely to require long-term ASC. In older adults, these syndromes are common, frequently co-occur and are associated with loss of independence.

The availability of a routine dataset combining health and social care data and the potential to apply a score prospectively to identify those who may need long-term ASC when there is still scope for prevention are attractive, given the relatively high annual cost of state-funded ASC—just under £20 billion in 2019–20. This is particularly important as long-term ASC is a largely demand-led service relying on people making their need known. The value of a model predicting new onset of ASC therefore lies in its ability to identify people at risk and otherwise unknown to local

Table 2. Baseline use of health services stratified by those who newly received long-term ASC arranged by the two local authorities in the 12-month follow-up period and those who did not

	Long-term ASC		Combined	
	Yes = 223	No = 13,171	n = 13,394	P
Number of emergency admissions				
0	135 (60.5%)	11,475 (87.1%)	11,610 (86.7%)	P < 0.001
1	51 (22.9%)	1,205 (9.1%)	1,256 (9.4%)	
2 or more	37 (16.6%)	491 (3.7%)	528 (3.9%)	
Number of Day elective				
0	189 (84.8%)	11,108 (84.3%)	11,297 (84.3%)	P = 0.88
1	24 (10.8%)	1,377 (10.5%)	1,401 (10.5%)	
2 or more	10 (4.5%)	686 (5.2%)	696 (5.2%)	
Average episodes per spell				
0	117 (52.5%)	9,623 (73.1%)	9,740 (72.7%)	P < 0.001
1	79 (35.4%)	3,123 (23.7%)	3,202 (23.9%)	
2 or more	27 (12.1%)	425 (3.2%)	452 (3.4%)	
Number of active outpatient specialties				
0	43 (19.3%)	4,772 (36.2%)	4,815 (35.9%)	P < 0.001
1–2	39 (17.5%)	2,341 (17.8%)	2,380 (17.8%)	
3–6	63 (28.3%)	2,767 (21.0%)	2,830 (21.1%)	
7 or more	78 (35.0%)	3,291 (25.0%)	3,369 (25.2%)	
A&E arrivals by ambulance				
0	146 (65.5%)	11,607 (88.1%)	11,753 (87.7%)	P < 0.001
1	46 (20.6%)	1,148 (8.7%)	1,194 (8.9%)	
2 or more	31 (13.9%)	416 (3.2%)	447 (3.3%)	
Number of X-ray Investigation				
0	162 (72.6%)	11,830 (89.8%)	11,992 (89.5%)	P < 0.001
1	40 (17.9%)	1,062 (8.1%)	1,102 (8.2%)	
2 or more	21 (9.4%)	279 (2.1%)	300 (2.2%)	

Table 3. Performance of logistic regression models trained with imbalanced versus resampled data

	Accuracy	AUC	Sensitivity (%)	Specificity (%)
Imbalanced data	0.984	0.738	0.000	1.000
Down-sampled data	0.687	0.692	0.606	0.688
Up-sampled data	0.735	0.752	0.651	0.737
SMOTE	0.846	0.742	0.439	0.852
ROSE	0.738	0.748	0.652	0.739

authorities. Models with most potential are those trained with ROSE and up-sampled data, both with sensitivity around 65% and specificity around 74%. This performance is, however, unlikely to be sufficient for these models to be adopted.

A previous attempt to predict older people likely to receive intensive social care using routine health and social care data, reported only modest accuracy [11]. The authors attributed the low sensitivity to the quality of data and the rarity of the outcome being predicted. They suggested that incorporation of further data on social and environmental factors may improve performance of ASC predictive models in future. A decade on, and despite the better availability of such data sets, the patchiness of data is still an issue and unlikely to be resolved. In addition, the complexity of individual and council decisions, variability of eligibility and personal circumstances may just not create enough common and

predictable patterns. Some of the most important factors in needing care in general are the sudden loss of informal care, a change in housing or financial circumstances, which are themselves difficult to predict.

Strengths and limitations

The study drew on population-level data for two London boroughs, using linked health and social care records, thus conveying a low risk of selection bias, other than through the lack of data on people who arranged social care privately. Focusing on two boroughs enabled us to work directly with the boroughs to validate data quality by checking coding at source and manually validating sampled cases.

Even with linked healthcare data at borough level, there is insufficient information and data for accurate individual-level prediction. Future attempts to develop models to
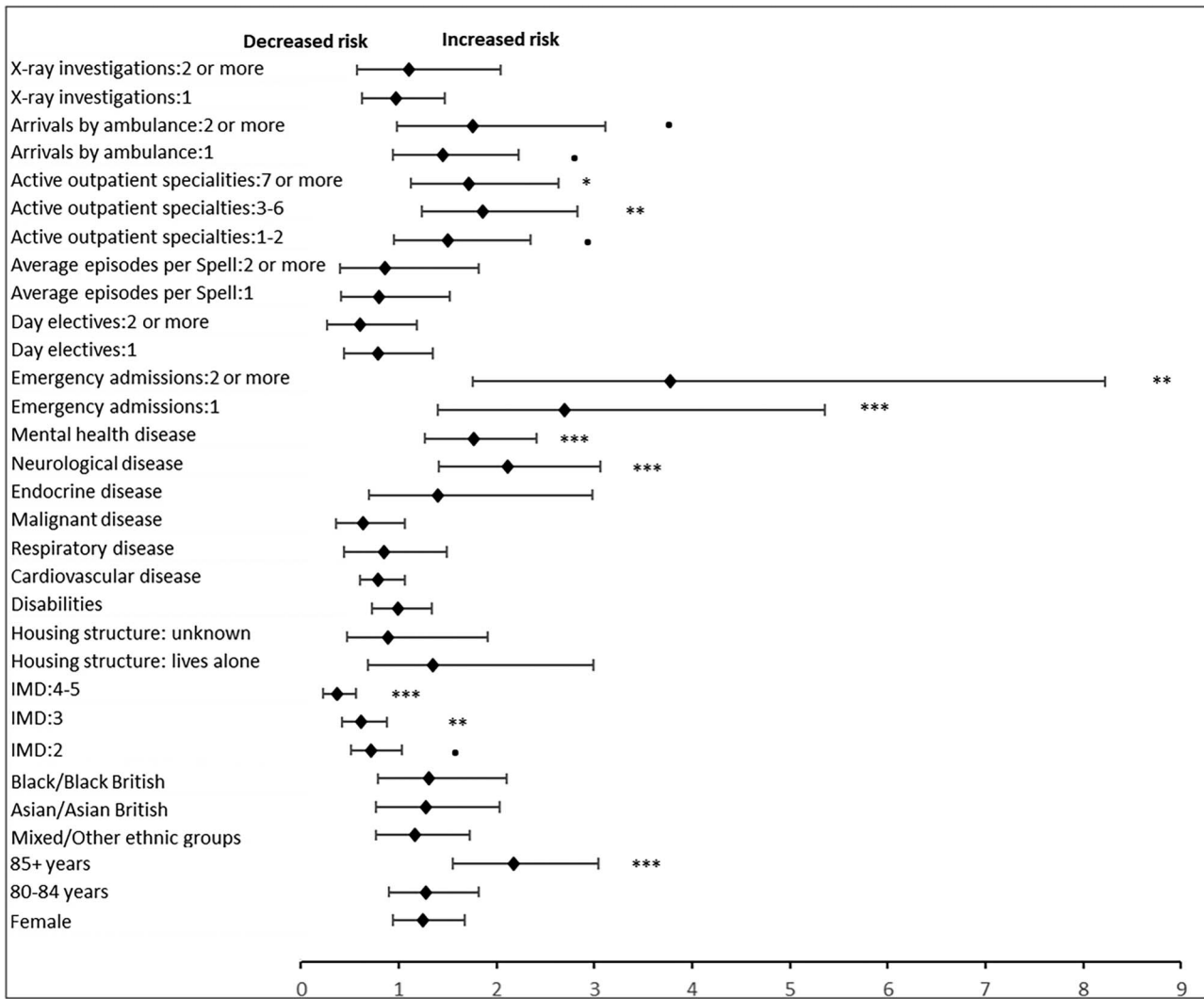
Figure 2. Odds ratio with 95% confidence limits. Significance codes: ***$P < 0.001$; **$P < 0.01$; *$P < 0.05$; •borderline significant $P < 0.1$.

predict onset of ASC should build on this work by using larger geographic scope and incorporating data around people's socioeconomic, social, personal and environmental factors.

Common to other similar studies based on routinely collected health and social care data, the data for this study were extracted from systems designed to support health and social care workers to deliver care, and hence may be of variable quality. Although improved recording may be beneficial for prediction models in the future, there are still limitations. We were missing key data on household structure. We did not have data on socioeconomic circumstances of individuals and no way of knowing whether someone funded their own care before accessing state funded care; these data are unlikely to become routinely available in future. We also do not have data on the availability of informal care to an individual through a spouse or family member, unless they make themselves known to the council. Informal care makes a major contribution to saving state funded care, in the

region of £132 billion per year, close to the whole NHS budget [24].

Although people who self-fund their care were outside the scope of this analysis, lack of data on such care may have influenced our model. In particular, it makes it impossible to distinguish between someone who is receiving ASC due to a change in need, from someone who pivots from self-funded care into state funded ASC due to a change in financial circumstances. This is relevant, because a change in eligibility criteria or the social landscape, for example austerity or economic change due to the current Covid-19 pandemic, might suddenly include a large number of people not previously anticipated needing care.

Policy implications

We demonstrate that it is possible to use administrative data to understand patterns of new ASC use for an ageing population. Our findings reenforce the need for upstream

prevention of mental ill health and neurological conditions such as stroke and dementia much earlier on. It also highlights the importance of levelling up socioeconomic inequalities. Our findings highlight potential for early intervention to prolong independence, improve quality of life and prevent NLTC.

Our findings confirm the apprehension of previous attempts to use model prediction for case finding, that there are inherent limits to statistical modelling and targeting, particularly in an area such as social care which relies on a plethora of moving parts, many of which are not well recorded and unlikely to be recorded in the near future. We propose a paradigm shift away from predicting need relatively late, to one of comprehensive, universal and integrated 'just in time' care tailored to the individual early on in the community. Self-reported characteristics such as 'difficulty walking', 'difficulty shopping' are known to be good predictors of needing long-term care in 12 months [5]. Similarly, data on ADL such as walking several blocks, bathing, dressing and managing personal finances identified those at risk of needing assistance at 2-years follow-up [21]. These data are neither routinely collected nor easy to collate, unless there is personal contact with the resident.

Relational approaches are much more likely to help implement effective and timely prevention going forward by enabling health and care providers to identify and respond in a timely manner to sudden loss of informal care, or a change in financial circumstances for an individual [25]. By identifying need and health risks early, such approaches can address inequality and allow effective implementation of changes way upstream in the community. A promising approach is the deployment of assertive universal and geography-based outreach, social prescribing and 'making every contact count', which provides a personalised approach to impactful interventions to avoid the loss of independence [26].

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