Impact of being an unpaid carer on health conditions and healthcare access in North West London

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Introduction

The Network Data Lab (NDL) is a pioneering collaborative network of analysts who use linked data, open analytics, and public and patient involvement to tackle the most pressing challenges in health and social care. The initiative is led by The Health Foundation working closely with five partner labs across the UK. The North West London Networked Data Lab (NWL NDL) is a partnership between Imperial College Health Partners (ICHP), North West London Health and Care Partnership, Imperial College's School of Public Health, and the Institute of Global Health Innovation (IGHI).

The overarching aim of the NDL is to improve health and care services, and reduce health inequalities in the UK, with the current project specifically aiming to understand the needs, health issues and pathways to services of unpaid carers.

Social care is provided by professional carers working in care homes, local services, etc., (estimated to be 1.5 million adult workers) and unpaid carers – children and adults who look after a family member, partner or friend who needs help because of their illness, frailty, disability, or a mental health issue. The number of unpaid carers is estimated between 7 and 13 million in England [1]. The value of the care that unpaid carers provide to the state is an estimated £132 billion a year – almost the equivalent of a second NHS.

With access to formal care services disrupted by the pandemic, unpaid carers are now under increasing pressure. 81% of unpaid carers in the UK are providing more care since the COVID-19 pandemic began, partly due to increased needs of the person they care for (40% of carers) and partly due to reduced local services (38% of carers) [2].

Many carers suffer from loneliness and isolation or face financial difficulties if they are unable to work alongside their caring role. Isolation, stress and performing caring are associated with poorer health. 36 out of 37 long-term conditions recorded in primary care in Wales were more prevalent among unpaid carers than non-carers, with the largest differences seen within cancer, depression and irritable bowel syndrome [3]. The COVID-19 pandemic worsened unpaid carers' health in the UK even more. 64% of them reported a decline in mental health and 56% in physical health as a result of the pandemic [2].

Patient and public involvement and engagement (PPIE) interviews and workshops with unpaid carers informed our analysis. Unpaid carers reported that they put the care for themselves second to that of the person they care for. They mentioned they were more likely to neglect their own care due to their caring responsibilities. This included cancelling or missing personal appointments. They may suffer from various health issues that may be exacerbated by their caring role, including back pain, fatigue, depression, anxiety, cardiovascular issues and high stress levels. Our public involvement work suggests that the COVID-19 pandemic may have led to increased hours spent caring after others, isolation and a deterioration of their mental health.

The aims of the study are to:

1. Explore the demographic profiles of unpaid carers as well as their geographical distribution in North West London
2. Estimate the effect of being a carer on health-related metrics and the risk of developing various long-term conditions
3. Analyse how the COVID-19 pandemic affects access of unpaid carers to healthcare services

To achieve these aims we extracted the healthcare data related to unpaid carers identified through a list of SNOMED codes in the Discover dataset. Discover data is the deidentified dataset which contains linked, coded primary care, secondary, acute, mental health, community health and social care records for over 2.5 million patients who live and are registered with a GP in North West London [4]. We also created a matched cohort based on gender, age, Index of Multiple Deprivation (IMD) and ethnicity to use as a control population for comparisons. The matched cohort contains professional carers, however, for brevity, in this study we refer to unpaid carers as carers and the matched population as non-carers.

Methods

Patient and Public Involvement and Engagement (PPIE)
To inform the questions we asked of the data, PPIE interviews with five unpaid carers were carried out. The Royal Borough of Kensington and Chelsea (RBKC) Carers UK group were contacted to recruit the carers who were interviewed. They represented people caring for different individuals (e.g., son, parent or husband) with different conditions (e.g., mental and physical needs). The questions asked, for example, were: “Have there been implications for your own physical or mental health that have arisen as a result of your caring role?”

One carer worked more closely with a data analyst to refine the research questions. The interim results were presented to a group of unpaid carers through the RBKC Carers UK group in an online workshop. The carers were asked if the results resonated with them, if anything surprised them, if there was anything missing from a carer perspective and where further research is needed. Quotes are used from the interviews and workshop to help make sense of the results.

Data extraction and pre-processing
All data used in this analysis was extracted from the Discover dataset.

Unpaid carers were defined using the SNOMED codes recently approved by The Health Foundation (Table 1).

Table 1. List of SNOMED codes used for identification of unpaid carers in NWL

SNOMED CODE	SNOMED TERM
224484003	Patient themselves providing care
276040005	Looks after someone
407543004	Primary carer
407542009	Informal carer
512321000000109	Assessment of needs offered to carer
824401000000105	Carer of person with dementia
962641000000100	Carer health check offered
302767002	Cares for a relative
413763001	Carer of a person with physical disability
413760003	Carer of a person with chronic disease
413761004	Carer of a person with learning disability
266946000	Looks after chronically sick relative
413762006	Carer of a person with mental health problem

224485002	Cares for a friend
276043007	Looks after chronically sick husband
276044001	Looks after chronically sick mother
276047008	Looks after elderly dependent
224486001	Cares for a neighbour
276045000	Looks after chronically sick spouse
276041009	Cares for mentally handicapped dependent
276042002	Looks after chronically sick father
276046004	Looks after chronically sick wife
276048003	Looks after physically handicapped dependent
413759008	Carer of a person with alcohol misuse
413764007	Carer of a person with sensory impairment
413765008	Carer of a person with substance misuse
151921000119105	Cares for sick or handicapped family member
248611000000108	Carer of a person with a terminal illness
288231000119101	Cares for dependent relative at home

We included data from February 2015 to May 2022, considering the period from February 2015 to February 2020 as the pre-COVID-19 pandemic period and data from March 2020 to May 2022 to reflect the COVID-19 pandemic since first lockdown was enforced in March 2020 in the UK.

Unpaid carers cohort: we included all patients in NWL aged over 18 from February 2015 to May 2022 who had at least one of the specified SNOMED codes for unpaid carers during the study period and did not have any of these codes within two years before the start of study (wash-out period). We implemented wash-out period to minimise the chances to include in the cohort those patients who were carers recently.

Control cohort: we also created a control cohort by matching each carer with up to five patients who did not have unpaid carer codes within the study period. Matching was based on gender, age, IMD decile and ethnic category. The matching was done using a set of consecutive rules (for each rule when more than five control patients were matched, five were selected randomly).

1) First, matching was done to get up to five control patients using gender, age, IMD decile and ethnic category

2) If none were matched based on the first approach, then matching was performed based on gender, age, IMD decile

3) If none were matched based on the second approach, then matching was performed based on gender, age, ethnic category and IMD decile, allowing IMD decile value to differ by one

Patients with missing data in the fields for age, ethnicity or IMD decile were removed from the cohort (<5% for carers cohort).

After matching, both unpaid carers and control cohorts had very similar gender, age, IMD decile and age distributions: mean age (control cohort – 60.0+/-20.4 (SD), unpaid carers – 60.1+/-20.44), mean IMD decile (both cohorts – 5.24+/-2.36 (SD)), percentage of females (both cohorts – 64%), ethnic distribution (both cohorts: 47% White, 32% Asian, 10% Black, 3% Mixed, 8% other ethnic groups).

For this study, we considered the following long-term conditions (LTCs) included in the Quality and Outcomes Framework [5]: ischaemic heart disease, hypertension, cancer, Parkinson's disease, diabetes, atrial fibrillation, heart failure, multiple sclerosis, chronic obstructive pulmonary disease (COPD), rheumatoid arthritis, chronic kidney disease, anxiety, dementia, strokes or transient ischaemic attacks (TIA), depression, epilepsy, learning disabilities, asthma and mental health conditions. We also extracted data for the electronic frailty index (eFI), patient activation measure (PAM) score and body mass index (BMI) as well as for prescriptions, A&E visits, GP visits, total outpatient appointments, and referrals by specialty.

For analysis of health metrics, health conditions and health care access, we included in the analysis only those events that happened after an unpaid carer received his/her first carer-related SNOMED code (the same date for respective controls). The rationale for that is that we wanted to assess the effect of being a carer on patients' health, therefore we aimed to analyse the incidence of long-term conditions after a patient was registered as a carer and compare with the matched controls. We address the drawbacks of this approach in the limitations section. All groups (unpaid carer + his/her matched controls) who did not have controls or carers were removed from the analysis. In case of PAM scores and BMI we used the most recent measurements.

Total counts with values lower than five have been suppressed in order to help anonymise results. More information can be found in the Handbook on Statistical Disclosure Control for Outputs [6].

Data analysis methods

Data analysis was conducted within the Discover secure data environment, using R version 4.2.1.

Matching was done using a Python script that was implemented in Python version 3.9.12 with Pandas 1.4.2. The Python environment was maintained using Anaconda.

The effect of being a carer on frailty, self-management and BMI

To study the effect of being a carer on eFI, PAM score and BMI, various multiple linear and logistic regression models were used where we adjusted for the effect of age, gender, IMD decile and ethnic group. The rationale for that was that we matched up to 5 controls to 1 carer, matching approach (described above) was not exact as well. For linear models we applied the square root or log transformation of the dependent variable as well as exponentiated or spline for age as a predictor. For logistic regression models we tested different thresholds for converting a continuous dependent variable to a binary one and showed the best performing model.

Here is the formula for basic linear/logistic regression:

> Dependent variable (eFI / PAM score / BMI) ~ carer status + age + gender + IMD decile + ethnicity category

Whereas age and IMD decile are numerical variable, carer status, gender and ethnicity category are categorical variables.

We report the odds ratios (or exponentiated coefficient in case of linear model with log transformed BMI), confidence intervals and p values corresponding to the carer status. Model estimates and confidence intervals were calculated using the stats (4.2.1) and jtools (2.2.1) packages.

Age-sex standardised rates for long-term conditions

We calculated age-sex standardised rates for each of the long-term conditions included in the analysis (see data extraction and pre-processing). Only patients with a first diagnosis of these conditions after becoming a carer during our study period were considered for the analysis. Due to small numbers of patients with overall mental health conditions category, they could not be included in the final analysis. However, data for anxiety, depression and learning disabilities were available and analysed.

For this analysis we split the unpaid carer and non-carer population by sex (male, female) and age group (0-19, 20-29, 30-39, 40-49, 50-59, 60-69, 70-79, 80+), and obtained counts of individuals diagnosed with each long-term condition per sex and age group. We then compared these counts with the corresponding total population (all individuals per sex and age-group) in NWL (using the corresponding data published by the Office for National Statistics) in order to conduct a direct standardisation of the rates per long-term condition as well as the number of conditions suffered by the population (classified as no long term conditions, one, two, or three or more concurrent conditions). Once we calculated these rates, we calculated rate ratios to estimate the difference in likelihood of developing each of these, using non-carers as the reference group. Functions from the epitools package (V 0.5-10.1) were used to conduct this analysis.

The effect of being a carer on health care access

Negative binomial and logistic regressions were used to study the effect of being a carer on prescription counts, A&E, outpatient and GP visits. We adjusted for the effects of age, gender and IMD decile in these models.

For the negative binomial analysis, we split the unpaid carer and non-carer population by sex (male, female), age groups (18-40, 41-55, 56-70, 71+), IMD deciles (1-10). We also used models with age as a continuous variable. Here is the formula for the negative binomial regression:

Dependent variable (visits / prescriptions) ~ carer status + age + gender + IMD decile + offset(logpop)

…in which “logpop” is the natural logarithm of the population.

For the logistic regression, age and IMD deciles were used as continuous variables whereas gender and carer status as binary ones. Here is the formula for the logistic regression:

Dependent variable (visits / prescriptions) ~ carer status + age + gender + IMD decile

We report the incidence rate ratios for carer/non-carer obtained from the model, 95% confidence intervals and p values corresponding to the carer status. Model estimates and confidence intervals were calculated using the MASS (7.3-57) and jtools (2.2.1) packages.

Impact of the COVID-19 pandemic on specialist referrals
We conducted an interrupted time series analysis to determine the difference in quarterly specialist referrals that occurred during our study period. For our analysis we considered that the COVID-19 pandemic started 1 March 2020 (Howarth et al. showed that healthcare service use dropped at least 13% in March 2020). We included the following specialties in our analysis as we had sufficient counts per quarter to create our models: cardiology, ophthalmology, trauma & orthopaedics, gynaecology, diagnostic imaging, ear, nose & throat, general surgery, dermatology, midwifery, respiratory medicine, urology, gastroenterology, general medicine, breast surgery, neurology, physiotherapy, colorectal surgery, vascular surgery, and rheumatology. For each specialty, we constructed a negative binomial model as follows:

Quarterly referrals ~ population size + time + carer status + pandemic + pandemic & carer indicator

Where:

- Population size: used as an offset variable that accounts for the number of unique patients per quarter. This variable is used as a natural logarithm of the count
- Time: yearly quarters since start of analysis
- Carer status: binary variable (unpaid carer, non-carer)
- Pandemic: binary variable indicating if the COVID-19 pandemic has already started (March 2020 or later)
- Pandemic & carer: a binary variable that indicates if the COVID-19 pandemic has started and the person is a carer.

In our models we assume the effect of the COVID-19 pandemic to be a change in level only. From these models, we are using:

- The coefficients from the carer status variable as a proxy for the pre-pandemic difference between unpaid carers and non-carers
- The coefficient from the pandemic variable as an indicator of the overall change seen during the COVID-19 pandemic
- The pandemic & carer indicator as a proxy for the difference between unpaid carers and non-carers after the COVID-19 pandemic started

Models were created using the *MASS* package (7.3-58), and estimates and confidence intervals were calculated using the *broom* package (V 1.0.0).

Results

1. Descriptive analysis of unpaid carers cohort

In the first part of the analysis, we aim to look at our unpaid carer population in North West London (NWL), and explore their demographics, geographical variations, and the impact of COVID-19 on the unpaid carers' healthcare utilisation.

Demographic characteristics of the unpaid carer population
Analysis of the selected cohort of unpaid carers across NWL clearly shows that a large proportion of carers are identified as females (64%). The overall NWL population has a slightly higher number of registered males (52%) than females (48%). This clearly indicates that a large proportion of unpaid carers are females across NWL (Figure 1).

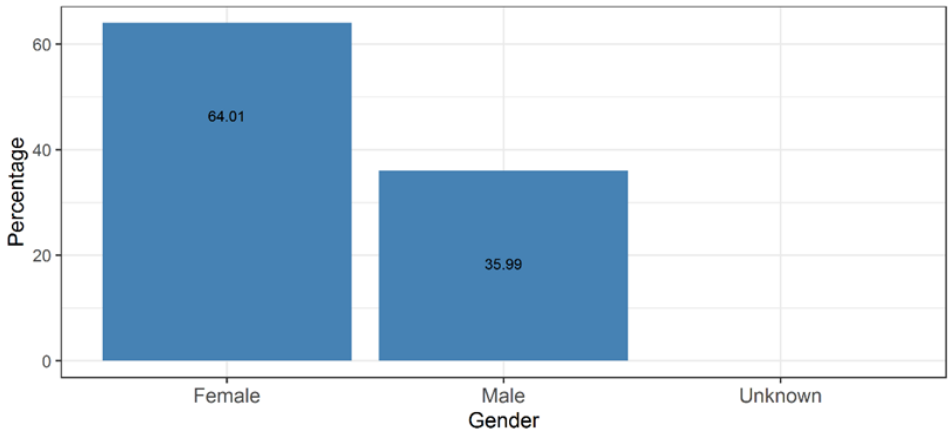


Figure 1: The percentage of unpaid carers cohort by gender across NWL. Numerator - unpaid carers by gender. Denominator - Total unpaid carers population across NWL.

Figure 2 below shows the breakdown of unpaid carers by age group. Age groups 80+ age and 50-59 have the highest shares of carers. It can also be concluded that older age groups have a larger proportion of people who identify as unpaid carers compared with younger age groups.

Figure 2 below also shows the split of gender by age group. We can see that the proportion of female representation in most age groups is higher than their male counterpart, reflecting their higher percentage of total unpaid carers. It can also be concluded that in younger age groups, the representation of female carers is almost doubled compared with males.

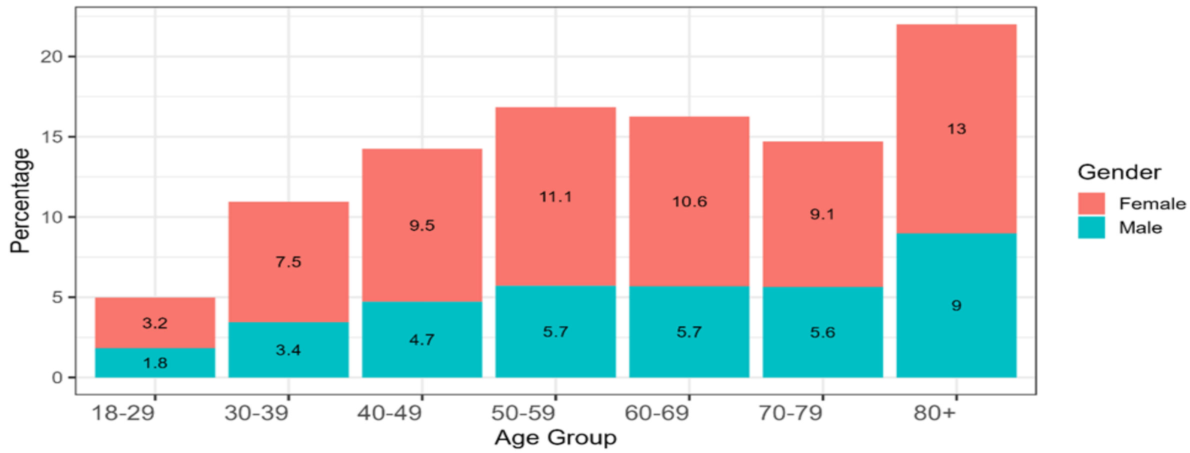


Figure 2: Unpaid carers gender percentage by age group. Numerator - the number of unpaid carer cohort by gender and age group. Denominator - total unpaid carer population of NWL.

Looking at the ethnicity of unpaid carers, as shown in Figure 3 below, the ethnic group identified as White represents the largest proportion of unpaid carers (47%) followed by Asians or British Asians (32%).

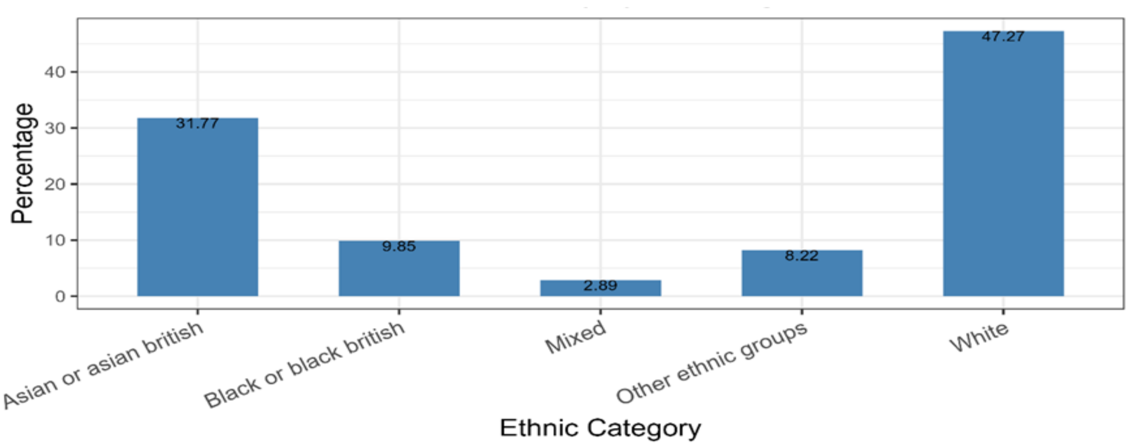


Figure 3: Unpaid carers percentage split by ethnicity. Numerator - the number of unpaid carer cohort in each ethnic group. Denominator - total unpaid carer population of NWL.

As shown in Table 2 below, when we look at the overall registered population of NWL by ethnicity, the findings above are reflected, as these two ethnic groups make up the largest proportion of the NWL population. Through PPIE work, unpaid carers mentioned that perhaps some cultures are more likely to live with older family members and carry out the role of a carer and interpreter for their loved ones. However, they might not always see themselves as a carer or report it to their GP. They noted that some ethnic groups might be from more disadvantaged backgrounds, be less likely to navigate the social care system, and not able to afford private carers.

Table 2: Unpaid carers and NWL registered population ethnicity breakdown. This table shows the comparative ethnicity breakdown for unpaid carer cohort and the overall NWL registered population. For NWL population, numerator – number of each ethnic group in NWL population, denominator – total NWL population.

Ethnicity	**Unpaid Carer**	**Overall NWL**
White	47%	43%
Asian or Asian British	32%	27%
Black or Black British	10%	8%
Other ethnic groups	8%	12%
Mixed	3%	4%
NULL	0%	6%

With regards to Index of Multiple Deprivation (IMD) information for the unpaid carer cohort, Figure 4 demonstrates that a large proportion of unpaid carers are residing in the slightly to highly deprived areas of NWL rather than the extremes.

Please note: Deciles are calculated by ranking the Lower Layer Super Output Areas (LSOAs) from most deprived to least deprived and dividing them into ten equal groups. These range from the most deprived 10% (Decile 1) of small areas nationally to the least deprived 10% (Decile 10) of small areas nationally.

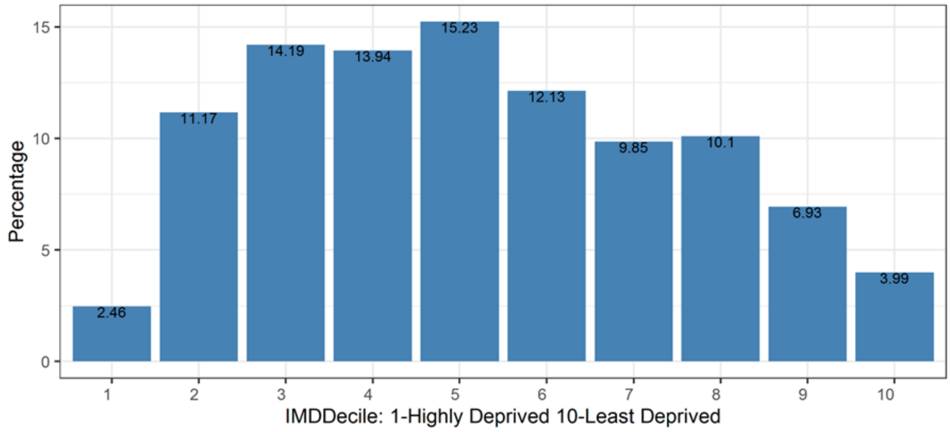


Figure 4: Unpaid carers percentage split by IMD decile. Numerator - number of unpaid carers belonging to each IMD Decile. Denominator - unpaid carer population of NWL.

When looking at the gender breakdown of the unpaid carers by IMD decile they reside under, we can see that there is a slight increase in the proportion of male representation when we look at least deprived deciles (Figure 5).

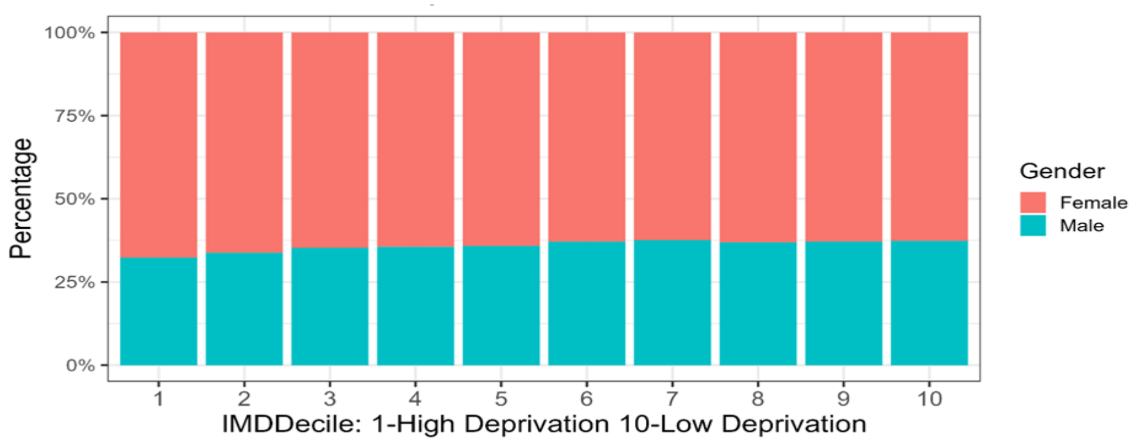


Figure 5: Unpaid carers' gender proportions in each IMD decile. Numerator - number unpaid carer population by gender and IMD. Denominator - total unpaid carer population.

Figure 6 shows the unpaid carer population in each IMD Decile split by age group. It can be seen that more deprived deciles have a higher share of younger carers

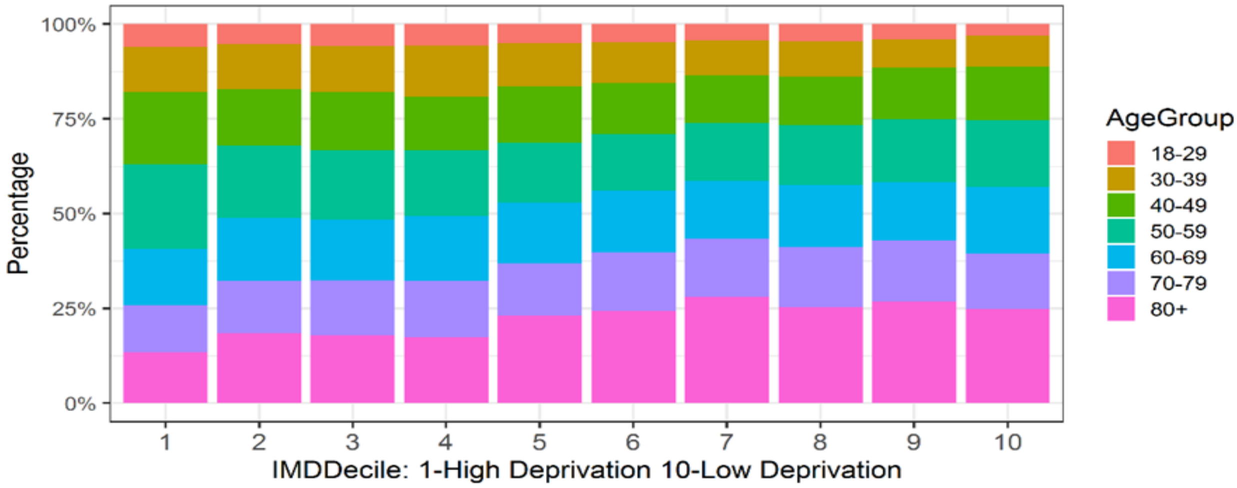


Figure 6: Unpaid carers' age group proportions in each IMD decile. Numerator - number unpaid carer population by age group in each IMD decile. Denominator - total unpaid carer population.

Geographical variations in the amount of unpaid caring at the borough level

The proportion of unpaid carers across NWL is shown in Figure 7 below. The London Borough of Harrow represents nearly a quarter of all unpaid carers (24.2%), followed by Brent (17.2%). Overall, outer London boroughs have significantly larger proportions of unpaid carers compared to inner London boroughs such as Westminster, Hammersmith & Fulham, and Kensington & Chelsea. Please note that the borough listed as "other" is where patients are registered with an NWL practice but reside outside the NWL borough.

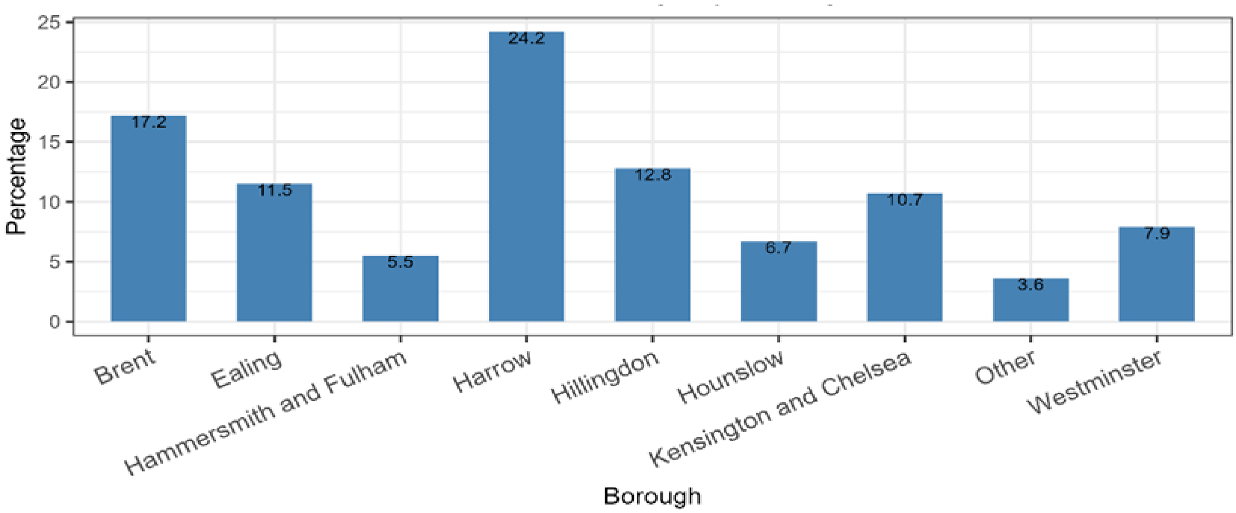


Figure 7: Unpaid carers percentage by boroughs. Numerator - number of unpaid carers in each borough. Denominator - total unpaid carer population of NWL.

Figure 8 shows the breakdown of NWL unpaid carers by borough and gender. Representation of female unpaid carers in all the boroughs is consistently higher or even double in some boroughs than that of males.

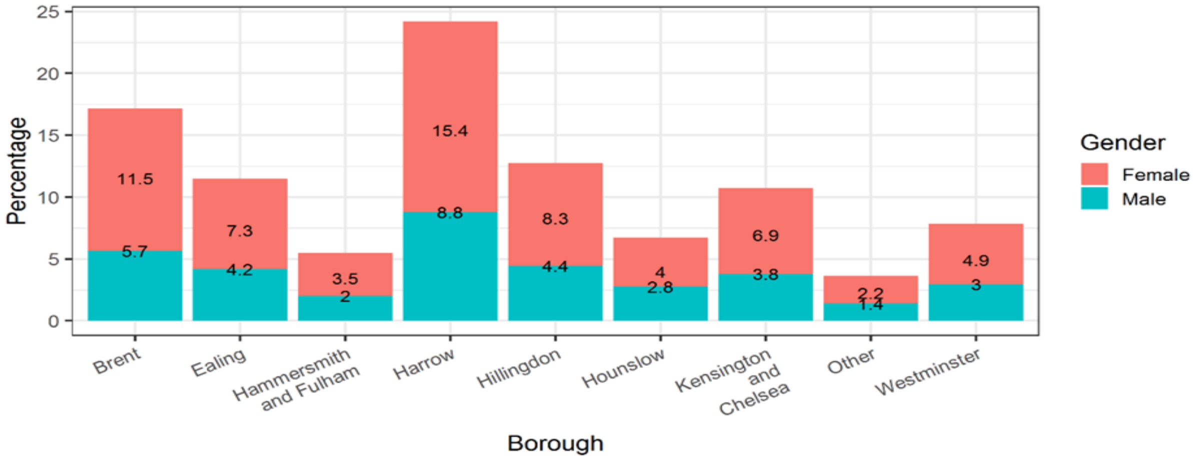


Figure 8: Unpaid carer percentage split by borough and gender. Numerator - number of unpaid carers across each borough split by gender. Denominator - total unpaid carer population of NWL.

Figure 9 shows the distribution of the unpaid carer population compared with the overall NWL population. We can see that while some boroughs may have roughly similar distributions of overall populations and unpaid carer populations (such as Hillingdon, Brent, Kensington & Chelsea, and Westminster), there are others in which there may be less unpaid carers compared with the NWL population (Hounslow, Hammersmith & Fulham). One borough, Harrow, had a larger share of unpaid carers compared with its overall share of the population (25.1% and 11.9%, respectively).

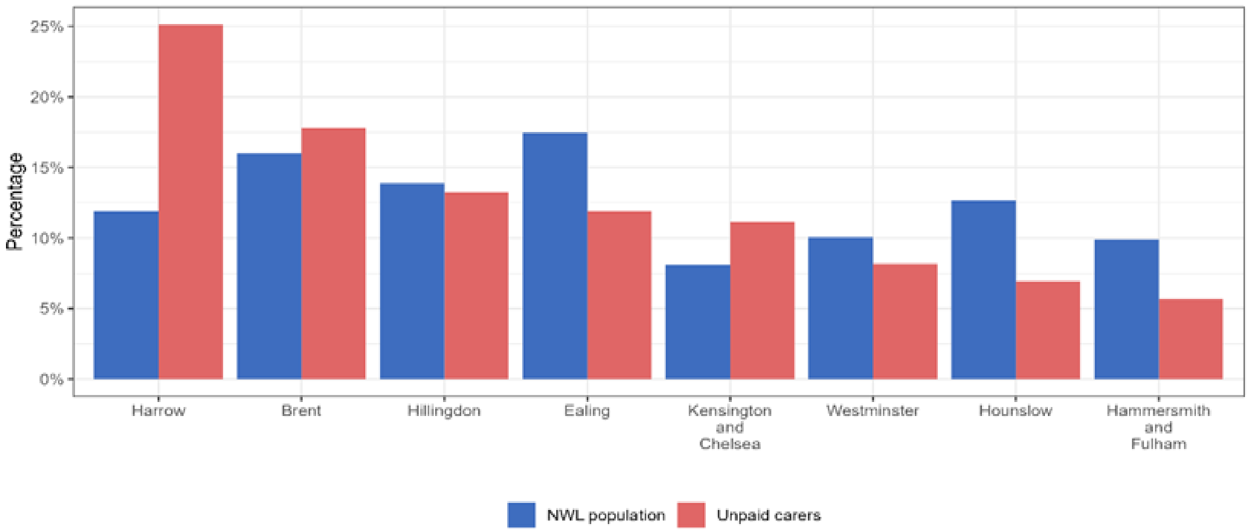


Figure 9: Unpaid carer and NWL population distribution by borough. Numerators - populations of NWL and unpaid carers by borough. Denominators - total number of unpaid carer and total NWL population numbers.

In Figure 10, we see the distribution of the unpaid carers and overall NWL population by ethnicity category. Overall, we see that distribution of unpaid carers by ethnicity roughly matches that of the overall NWL population.

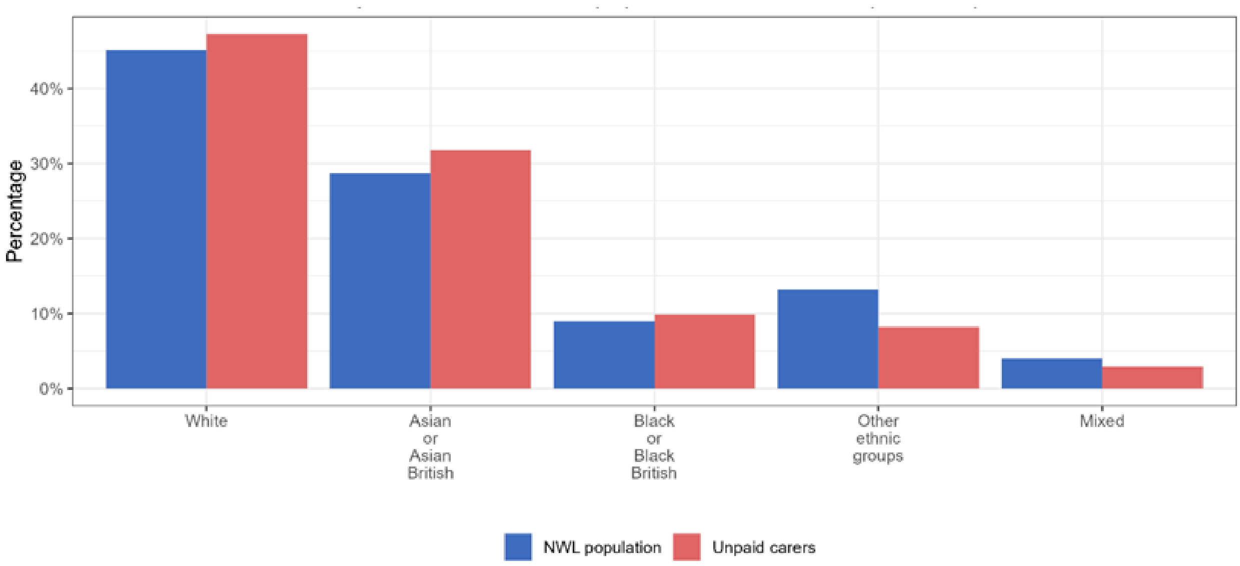


Figure 10: Unpaid carer and NWL population distributions by ethnicity. Numerators: - populations of NWL and unpaid carers by each ethnic group. Denominators - numbers of total unpaid carers and total NWL populations.

Figure 11 shows the distribution of the unpaid carer population and NWL population by ethnicity category per borough. Overall, we can identify that per-borough populations split by ethnicity are roughly matched for our unpaid carer and NWL population. However, there seem to be a slightly higher share of White unpaid carers in Hillingdon and Harrow, Asian and Asian British unpaid carers in Ealing, and Black and Black British unpaid carers in Hammersmith and Fulham.

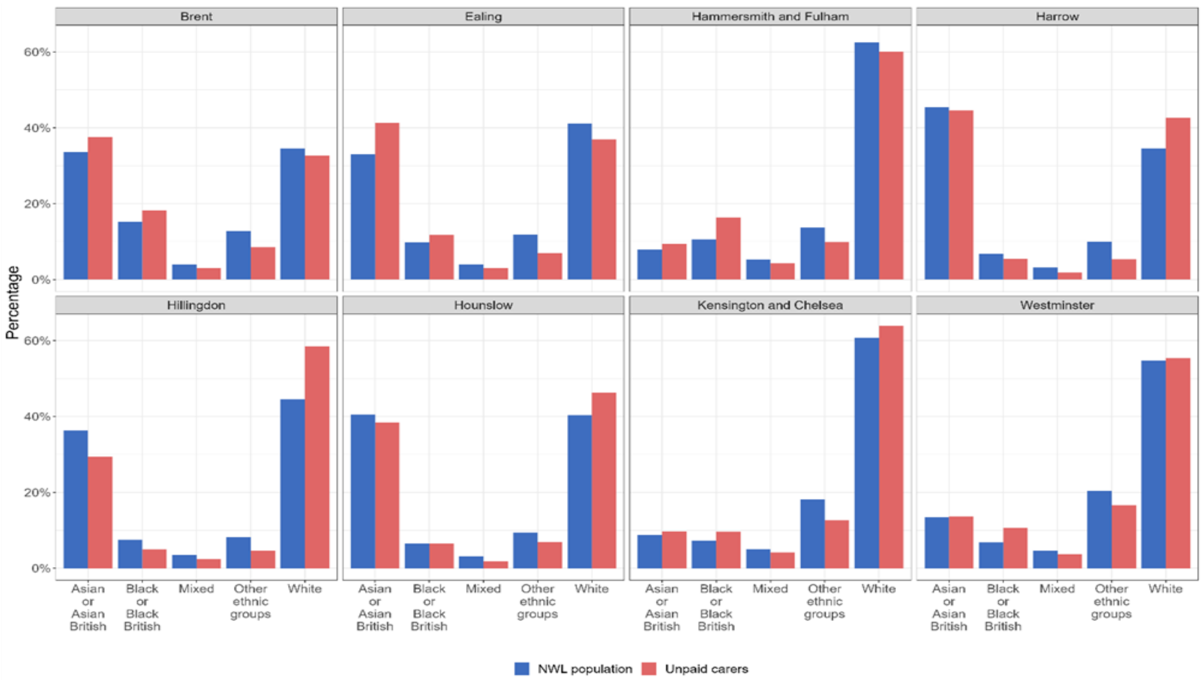


Figure 11: Unpaid carers and NWL population distributions by ethnicity and borough. Numerators - numbers of unpaid carers and overall population split by borough and ethnic group. Denominators - total number of unpaid carers and overall NWL population split by borough.

Impact of the COVID-19 pandemic on healthcare utilisation by unpaid carers

In this section we describe the effect of the COVID-19 pandemic on healthcare access for the unpaid carer population (measured in A&E/primary care visits, primary care prescriptions issued, and outpatient visits). PPIE work suggested that isolation, stress, anxiety and depression were compounded by the pandemic. One unpaid carer mentioned her mother is a practicing Muslim and has dementia. Attending the mosque is her social outlet and important for her spiritual health. However, the mosque was closed during COVID-19, which impacted the level of social interaction the mother had and stress level for both the carer and mother. Another mentioned they were petrified to go out into the community and therefore for one month lived on one meal a day. Carers said their anxiety increased around ensuring prescriptions would arrive in time for loved ones. For example, they had to collect prescriptions or change delivery slots, as no one could come into the house, for fear of passing COVID-19 on to their loved ones. Others said that professional care (e.g., rehabilitation physiotherapy for their loved one) and respite care was hard to come by, which led to increased caring hours and fatigue.

As shown in Figure 12, there is a noticeable dip in primary care interactions at the start of the COVID-19 period after February 2020. The rate of visits to primary care seems to experience continuous growth till the start of the COVID-19 period, but since then it has come down and has not exceeded the pre-pandemic level.

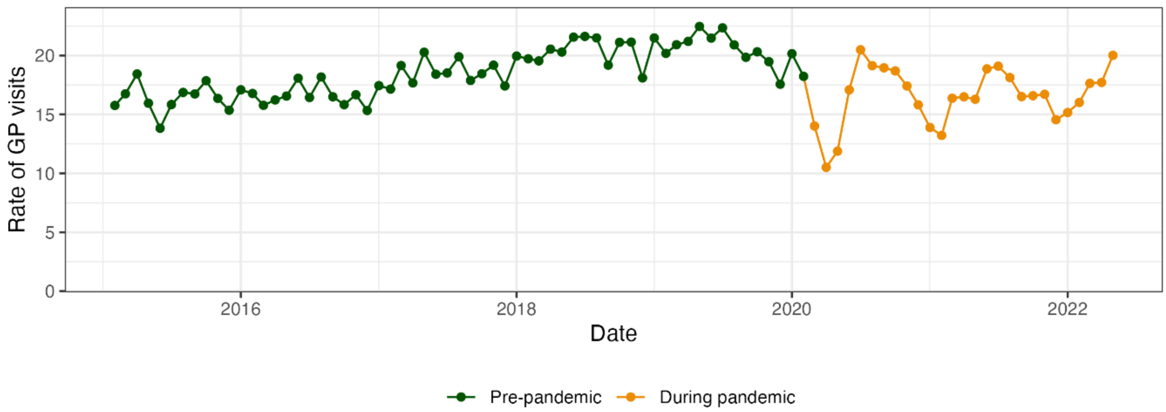


Figure 12: Rate of GP visits per month by unpaid carers February 2015 – May 2022. Numerator - number of visits per month, denominator - unpaid carer number for that month.

In regard to A&E visits for the unpaid carer population, Figure 13 shows the rate of unpaid carers attending A&E services was not significantly affected by the COVID-19 pandemic.

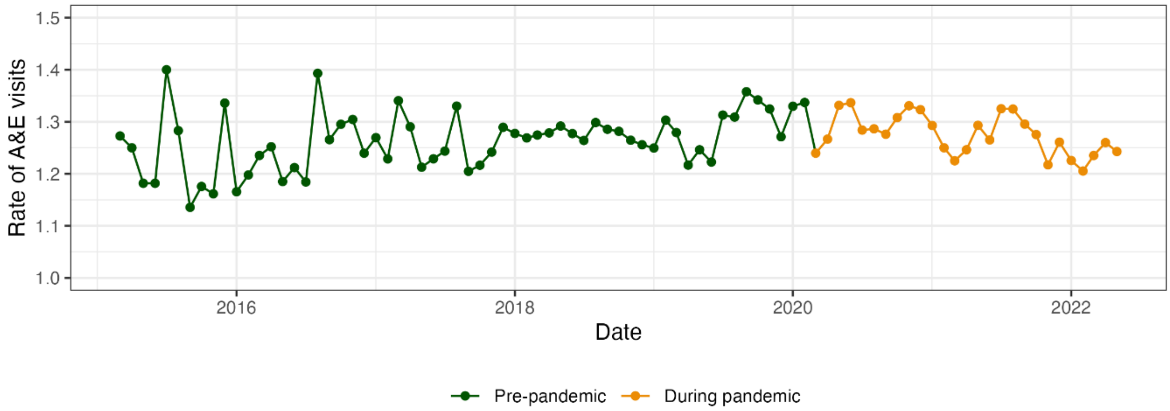


Figure 13: Rate of A&E visits in unpaid carers population March 2015 – May 2022. Numerator - number of visits per month, denominator - unpaid carer number for that month.

Outpatients (OP) visits rates were relatively stable from April 2016 till the start of the pandemic, then slightly dropped during first months of the COVID-19 pandemic, and it looks like there is an increasing trend. However further monitoring is required for conclusions (Figure 14).

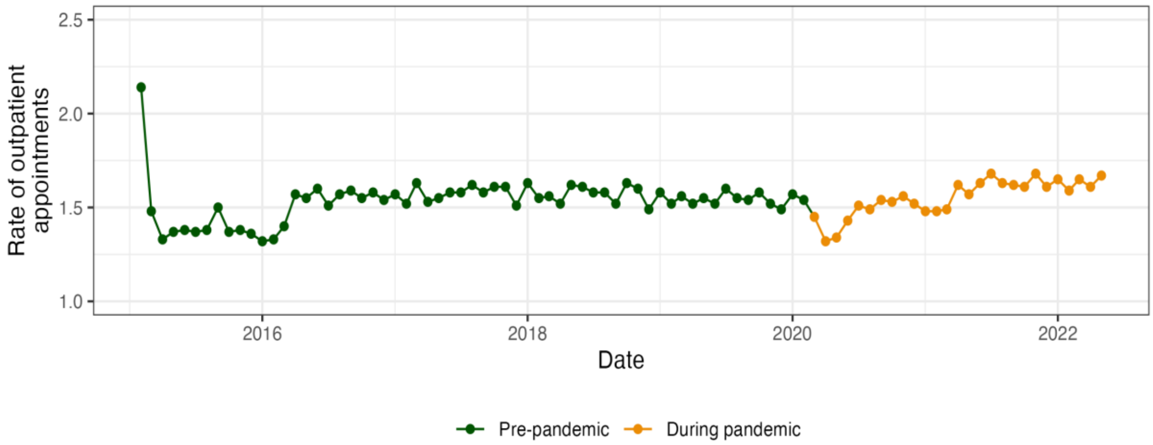


Figure 14: Rate of OP visits in unpaid carers population February 2015 – May 2022. Numerator - number of visits per month, denominator - unpaid carer number for that month.

Figure 15 demonstrates that the rate at which GP prescriptions were issued to unpaid carers peaked during the middle years of study period and have seen decline in the post COVID-19 period.

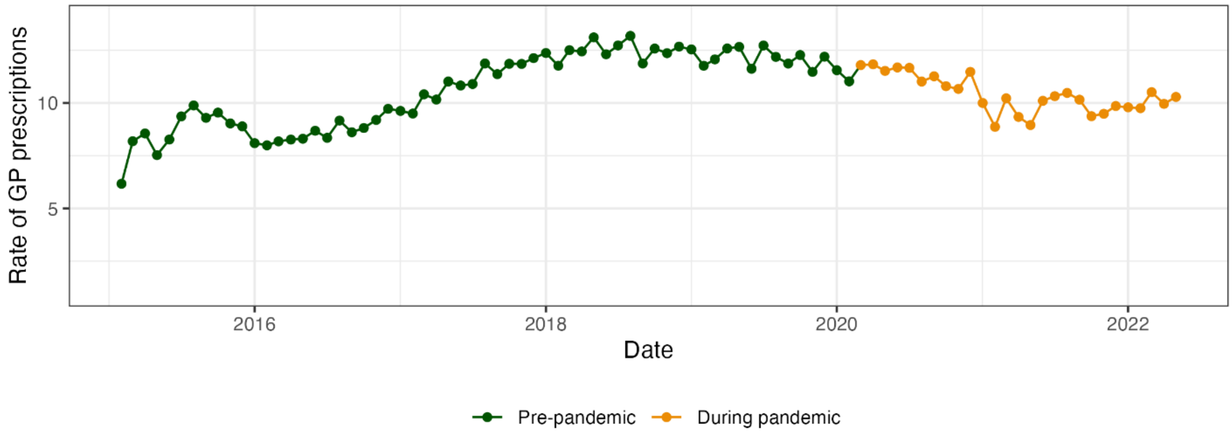


Figure 15: Rate of prescriptions issued for unpaid carers population February 2015 – May 2022. Numerator - number of prescriptions per month, denominator - unpaid carer number for that month.

2. Analysis of health conditions more prevalent in unpaid carers and the effect of COVID-19

Health of unpaid carers before they were identified as carers

Before studying the effect of being an unpaid carer on various health metrics and conditions, we first looked at the prevalence of various LTCs among unpaid carers (and matched non-carers) before unpaid carers were identified. We can see on the Figure 16A that all LTCs studied are more prevalent among future unpaid carers, and the difference is particularly high for learning disabilities (4.3x increase), epilepsy (2.1x increase), stroke (2x increase) and depression (1.8x increase). Higher proportions of future unpaid carers also have one, two or more than three LTCs (Figure 16B). This suggests that the cohort of people who were to become unpaid carers have much poorer health on average.

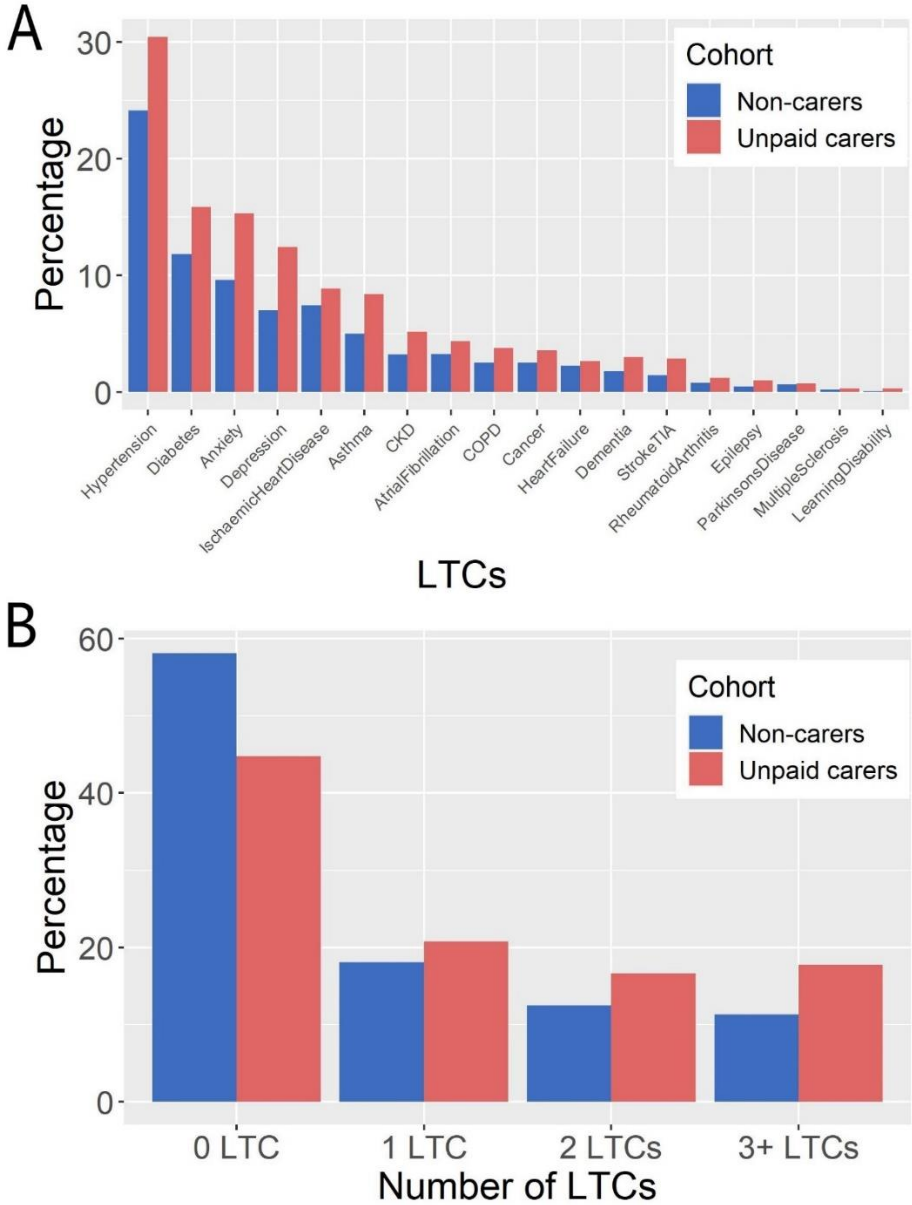


Figure 16: Percentage of unpaid carers and matched non-carers diagnosed with long-term conditions (LTCs) before unpaid carers were identified as such. A) Prevalence of long-term conditions included in the Quality and Outcomes Framework among carers and non-carers, B) Distribution of the numbers of LTCs among carers and non-carers.

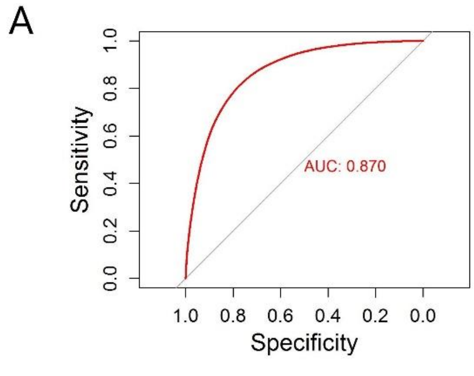
The effect of being a carer on frailty, BMI and self-management

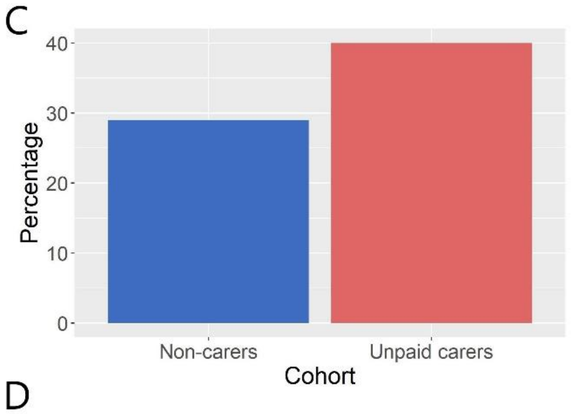
As well as long-term conditions, we looked at the eFI (electronic frailty index), BMI (body mass index) and PAM score (patient activation measure score). The eFI is a clinically validated tool that can identify people with frailty on a population basis using routinely collected primary care data. The eFI uses a subset of Read codes to identify up to 36 potential deficits. Obese people are at increased risk of type 2 diabetes, hypertension, heart disease, stroke and total mortality. BMI and eFI are proxies of health status. PAM is a 13-item instrument that measures confidence in self-management and knowledge of health conditions.

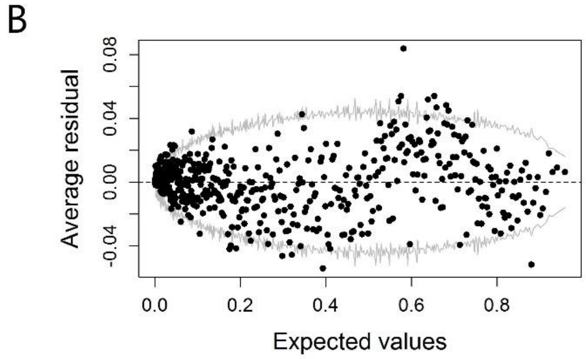
We used only the values measured after the date unpaid carers were identified as such (the same date for matched non-carers) and took the latest record when more than one were available.

We applied several linear and logistic models (see methods for details) using person-level data to assess the association between being an unpaid carer and these metrics, adjusting for gender, age (at the time of data extraction), IMD decile (at the time of data extraction) and ethnic categories. The best performing models in terms of outcomes of diagnostic tests are shown. Binned residual plot, ROC AUC plot and confusion matrix were used to assess logistic regression, whereas residuals versus fits plot, the scale-location plot, QQ plot, residuals vs leverage plot were used to evaluate linear regressions.

We first assessed the association between eFI and carer status. The best model was a logistic regression where we converted eFI score into a binary variable (severe or moderate eFI). 40% of unpaid carers had moderate or severe eFI compared with 27% among non-carers (Figure 17C). We can see that most of the binned residuals are within 95% confidence interval and the area under the receiving operating characteristic curve (ROC AUC) of the classifier is 0.87, see also confusion matrix (Figure 17A,B,D), which reflects good performance of the model. The model suggests that carers have 2.76 times higher odds of having moderate or severe eFI (Table 3).





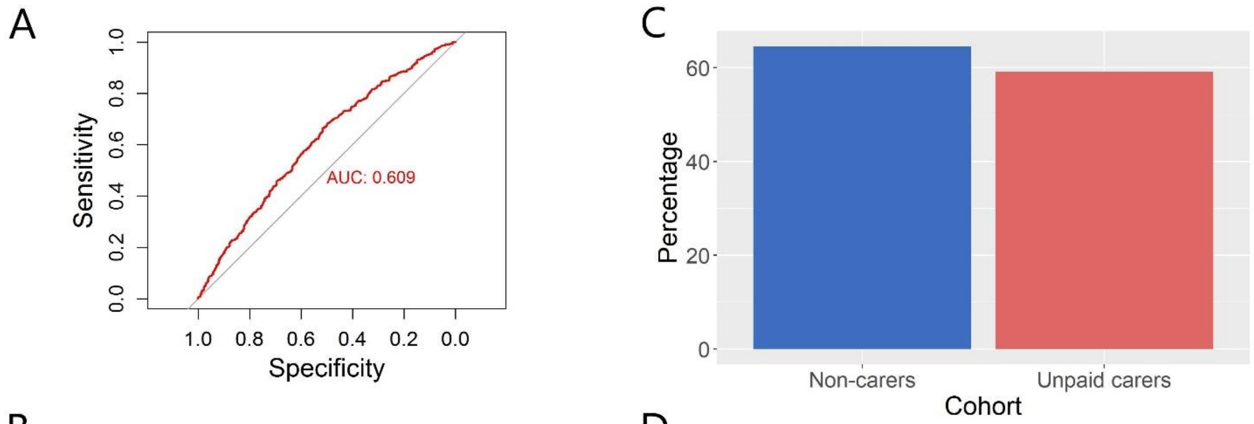


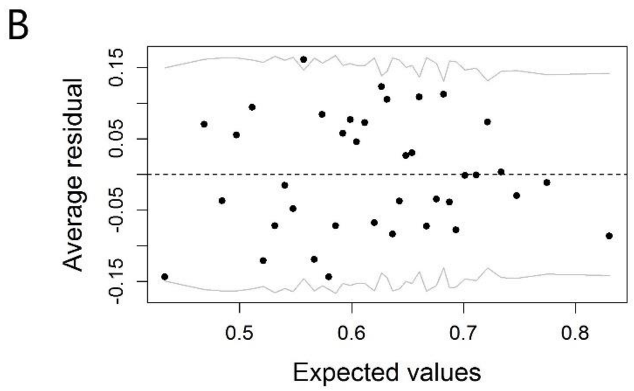
D

	Observed	
Predicted	Low eFI	Moderate/severe eFI
Low eFI	164,167	28,642
Moderate/severe eFI	22,252	53,567

Figure 17: Modelling moderate or severe eFI outcome with a logistic regression. A) ROC curve for the model, B) Proportions of patients with moderate or severe frailty index values, C) Binned residual plot for the model, D) Confusion matrix for the model.

Next, we assessed the association between PAM score and carer status. The best model was again a logistic regression where PAM score was converted into a binary variable (PAM score 50 or above). 59% of carers have PAM score 50 or above compared with 65% among non-carers (Figure 18C). The model's binned residuals are within 95% confidence interval and the ROC AUC is 0.61, see also confusion matrix (Figure 18A,B,D), which reflects good performance of the model. The model suggests that being a carer decreases the odds of having PAM score 50 or above by 22% (Table 3).





D

	Observed	
Predicted	Low eFI	Moderate/severe eFI
Low eFI	164,167	28,642
Moderate/severe eFI	22,252	53,567

Figure 18: Modelling PAM score 50 or above using a logistic regression. A) ROC curve for the model, B) Proportions of patients with PAM score 50 or above, C) Binned residual plot for the model, D) Confusion matrix for the model.

Finally, we assessed the association between BMI and carer status. In this case the best model was a linear regression where the dependent variable (BMI) was log transformed. Figure 19C shows that mean BMI almost does not differ between non-carers and carers. The residuals vs fitted and QQ plots suggest that the model performs well enough for interpretation (Figure 19A,B). The model suggests that being a carer increases BMI by only 1% (Table 3).

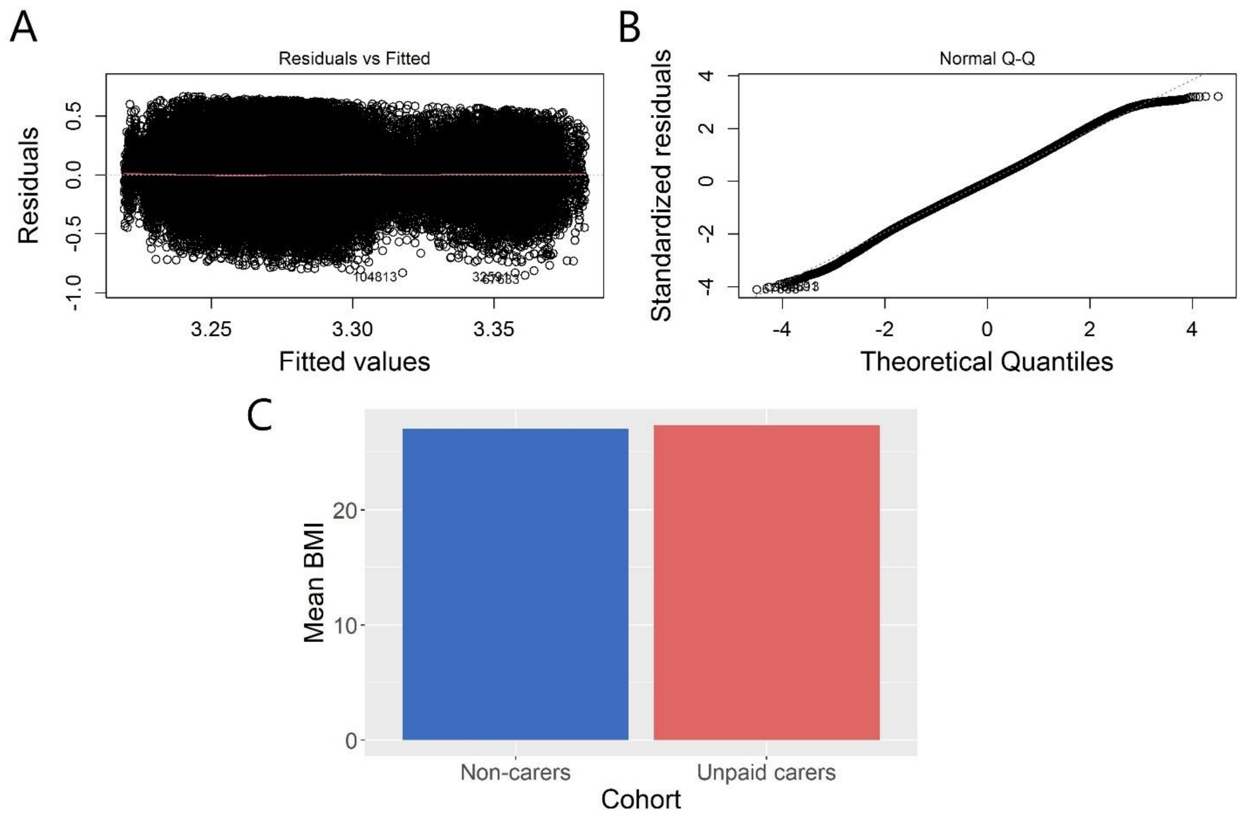


Figure 19: Modelling log (BMI) using linear model regression. A) Residuals versus fits plot, B) QQ plot, C) Mean BMI for non-carers and unpaid carers.

Table 3. Odds ratio for carers/non-carers with 95% confidence interval and p-values obtained using logistic regressions or exponentiated coefficient for the linear model where BMI values were log transformed.

Type of healthcare service	*Odds ratio (95% CI)*	*P-value*
Moderate or severe eFI	2.76 (2.68 – 2.83)	<0.001
PAM score 50 or over	0.78 (0.63 – 0.97)	0.026
	Exponentiated coefficient (95% CI)	*P-value*
BMI	1.011 (1.008 - 1.013)	<0.001

Age-sex standardised rates for long-term conditions

We calculated age-sex standardised rates of individuals having none, one, two, or three or more LTCs based on whether they were unpaid carers or non-carers in order to understand the overall burden unpaid carers may be exposed to as a result of their carer duties. Our analysis (Figure 20A) indicated that unpaid carers are 45.34% (41.91% - 48.85%, p < 0.001) more likely to have one LTC, 56.94% (49.84% - 64.38%, p < 0.001) more likely to have two

LTCs and 59.26% (45.28% - 74.60%, p < 0.001) more likely to have three LTCs or more. On the other hand, unpaid carers were 8.45% (7.49% - 9.41%, p < 0.001) less likely to not have any LTC.

We also calculated age-sex standardised rates for **individual long-term conditions** for our unpaid carer cohort and compared them with those for our non-carer matched cohort. Overall, unpaid carers were more likely than non-carers to suffer from all conditions with the exception of cancer and multiple sclerosis (Figure 20B). Unpaid carers were more likely to suffer:

- Hypertension (rate ratio = 1.10 (1.05-1.16, p<0.001))
- Diabetes (rate ratio = 1.26 (1.20-1.33, p = 0.001))
- Rheumatoid arthritis (rate ratio = 1.35 (1.12-1.62, p<0.001))
- Stroke or TIA (rate ratio = 1.38 (1.25-1.52, p<0.001))
- Ischaemic heart disease (rate ratio = 1.43 (1.33-1.54, p<0.001))
- Atrial fibrillation (rate ratio = 1.45 (1.36-1.56, p<0.001))
- Chronic kidney disease (rate ratio = 1.52 (1.43-1.61, p<0.001))
- COPD (rate ratio = 1.60 (1.43-1.78, p<0.001))
- Asthma (rate ratio = 1.60 (1-45 – 1.77, p < 0.0001))
- Dementia (rate ratio = 1.78 (1.66-1.93, p<0.001))
- Anxiety (rate ratio = 1.79 (1.70-1.88, p<0.001))
- Heart failure (rate ratio = 1.83 (1.70-1.97, p<0.001))
- Depression (rate ratio = 1.94 (1.82-2.07, p<0.001))
- Parkinson’s disease (rate ratio = 2.23 (1.84-2.70, p<0.001))
- Epilepsy (rate ratio = 2.44 (1.88-3.16, p<0.001))
- Learning disabilities (rate ratio = 5.64 (4.99-6.38, p<0.001)).

Consequently, unpaid carers had higher age-sex standardised rates for all these conditions. The five more prevalent conditions were diabetes (2,377 per 100,000 population for unpaid carers, 1,840 for non-carers), learning disabilities (2,576 per 100,000 population for unpaid carers, 350 for non-carers), depression (2,613 per 100,000 population for unpaid carers, 1,635 for non-carers), hypertension (2,995 per 100,000 population for unpaid carers, 2,650 for non-carers) and anxiety (4,724 per 100,000 population for unpaid carers, 2,667 for non-carers).

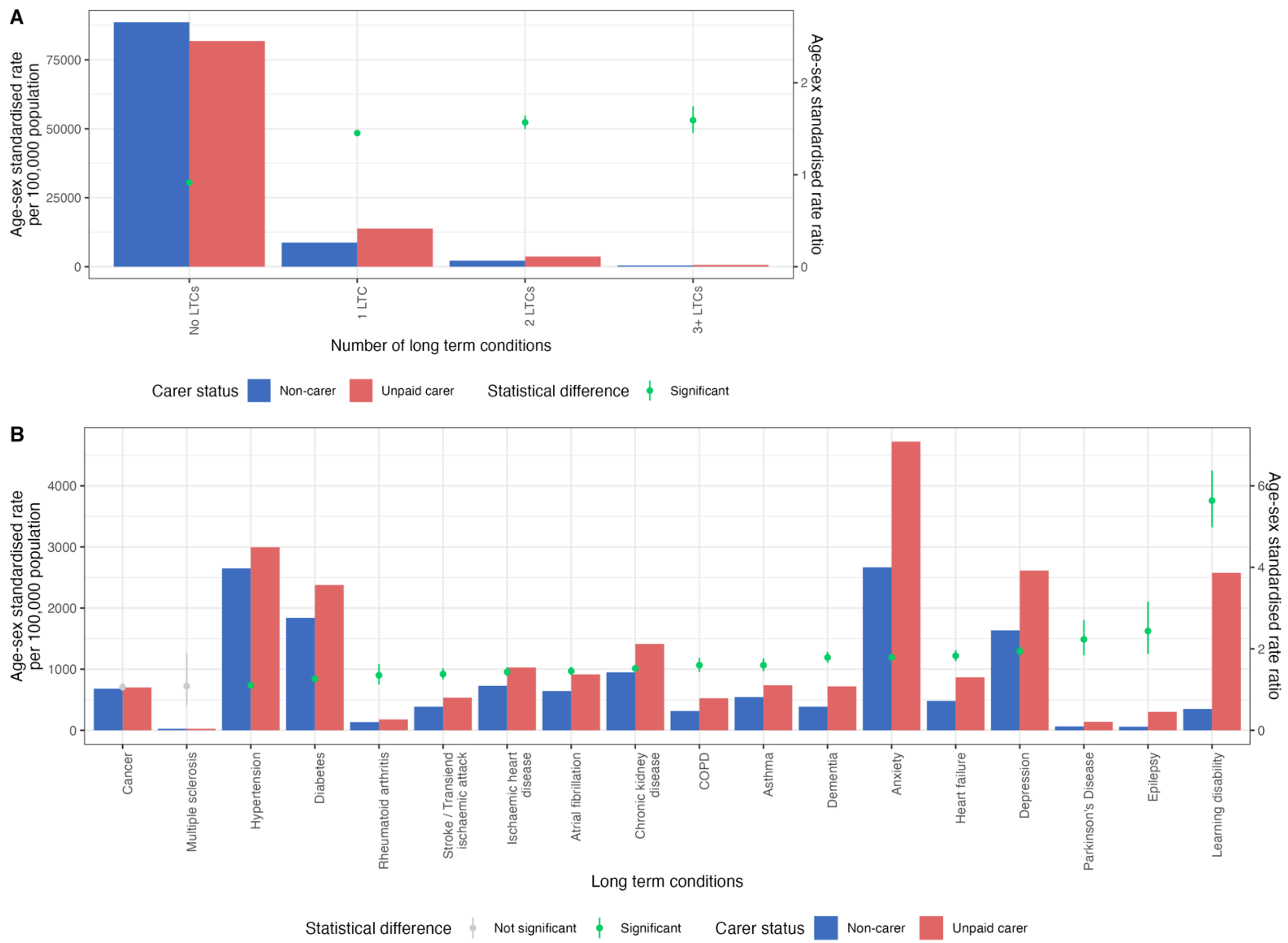


Figure 20: Age-sex standardised rates for long term conditions in unpaid carers and non-carers. Rates of disease per 100,000 population are shown bars (left Y-axis) for non-carers (blue) and unpaid carers (red). Disease rate ratios are shown as green dots (right Y-axis), and lines across dots indicate 95% confidence intervals. A) Number of long-term conditions, B) Individual long-term conditions

3. Analysis of healthcare services used by unpaid carers and the effect of COVID-19

The effect of being a carer on health care access

In this section, we studied how being a carer affects access to various healthcare services. We chose A&E, outpatient and general practice attendance as well as prescriptions. As with the previous analysis, we included only visits that happened after the date carers were identified.

Figure 21 shows that carers use all healthcare services more intensively than non-carers on average during the study period. The difference is particularly clear for GP visits and the number of prescriptions.

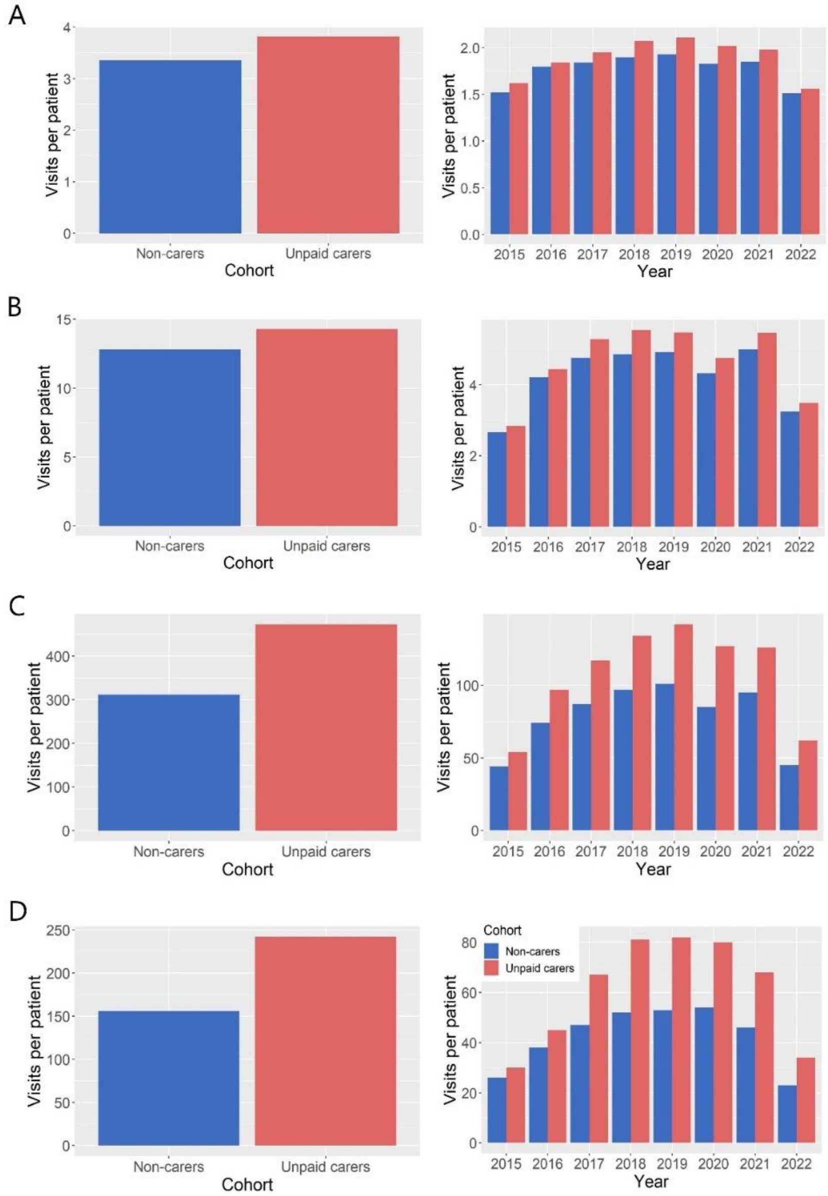


Figure 21: Visits/prescription per unpaid carer or non-carer. A) A&E visits, B) outpatient visits, C) GP visits, D) prescriptions. Numerator – number of visits, denominator – total population (unpaid carers or non-carers). Ratios calculated for all visits during the study period Feb 2015 – May 2022 (left chart), for each year with exceptions: Feb 2015 – Dec 2015 and Jan 2022 – May 2022 (right chart).

To model the effect of being an unpaid carer on healthcare utilisation we used various negative binomial and logistic regression models where age, gender and IMD decile were adjusted for. The diagnostic tests for negative binomial models were satisfactory, and the incidence rate ratios for being a carer are shown in the Table 4. One can see that being a carer increases the rate of visiting A&E, outpatients and GP by 18%, 16% and 57% respectively. Carers also have a 67% increase in the number of prescriptions. All the results are statistically significant.

Table 4. Incidence rate ratio for unpaid carers/non-carers with 95% confidence interval and p-values obtained using negative binomial models.

Type of healthcare service	Incidence rate ratio (95% CI)	P-value
A&E visits	1.18 (1.13 - 1.23)	<0.001
Outpatient visits	1.16 (1.11 - 1.22)	<0.001
GP visits	1.57 (1.48 - 1.66)	<0.001
Prescriptions	1.67 (1.58 - 1.78)	<0.001

The effect of being a carer and the COVID-19 pandemic on referrals by specialty rates

We estimated the difference in referral numbers per quarter pre- and post-COVID-19 pandemic, as well as the overall effect of the COVID-19 pandemic. Our analysis indicates that across all specialities included in the analysis, while there was a significant difference between the usage in all specialties prior to the pandemic between unpaid carers and non-carers, this difference decreased post-pandemic, but this was not statistically significant. Furthermore, the COVID-19 pandemic led to a significant decrease in referrals overall. A list of the changes measured across all specialities is listed in Table 5.

Using ophthalmology as an example for all specialities (Figure 22), unpaid carers had 63.78% ($p < 0.001$) fewer referrals that non-carers for this speciality. However, post pandemic this gap decreased though not statistically significantly. However, our model indicates that there was an overall decrease of 81.90% ($p < 0.001$) of referrals during the COVID-19 pandemic.

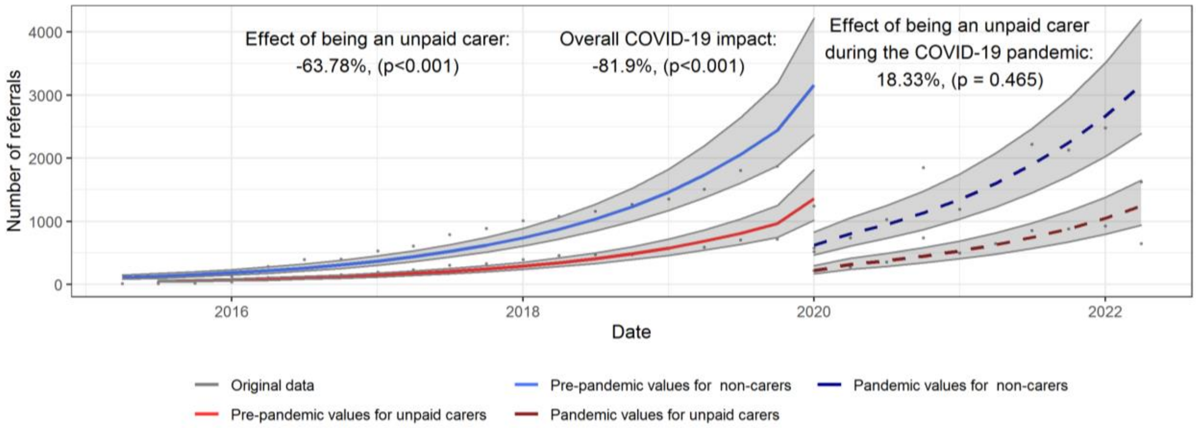


Figure 22: Model estimates for quarterly ophthalmology referrals. Grey dots indicate quarterly counts of referrals, light blue and red solid lines indicate model estimate pre-pandemic for non-carers and unpaid carers, respectively. Dark blue and red dashed lines indicate model estimates post-pandemic.

Table 5. Estimated pre-pandemic difference in number of specialist referrals between non-carers and unpaid carers, overall effect of the COVID-19 pandemic (for both unpaid carers and non-carers), and post-pandemic effectof being unpaid carer on referral appointments per specialty. For the pre- and post-pandemic effects, we are using non-carers as our reference category, hence, values shown on this table refer to changes observed for unpaid carers compared to the non-carer cohort.

Specialty	***Pre-pandemic difference***	***Overall COVID-19 impact***	***Post-pandemic effect of being unpaid carer***
Cardiology	-62.4% ($p < 0.001$)	-85.1% ($p < 0.001$)	26.1% ($p = 0.292$)
Ophthalmology	-63.78% ($p < 0.001$)	-81.9% ($p < 0.001$)	18.33% ($p = 0.465$)
Trauma & orthopaedics	-58.74% ($p < 0.001$)	-80.7% ($p < 0.001$)	13.29% ($p = 0.552$)
Gynaecology	-63.9% ($p < 0.001$)	-71.89% ($p < 0.001$)	19.28% ($p = 0.390$)
Diagnostic imagining	-64.72% ($p < 0.001$)	-80.53% ($p < 0.001$)	38.7% ($p = 0.197$)
Ear, nose & throat	-60.92% ($p < 0.001$)	-84.36% ($p < 0.001$)	21.08% ($p = 0.267$)
General surgery	-59.5% ($p < 0.001$)	-74.4% ($p < 0.001$)	8.54% ($p = 0.688$)
Dermatology	-62.62% ($p < 0.001$)	-77.1% ($p < 0.001$)	22.28% ($p = 0.199$)
Midwife episode	-51.9.0% ($p < 0.001$)	-33.53% ($p = 0.043$)	-24.91% ($p = 0.147$)
Respiratory medicine	-61.15% ($p < 0.001$)	-81.7% ($p < 0.001$)	37.57.% ($p = 0.105$)
Urology	-62.55% ($p < 0.001$)	-76.93% ($p <0.001$)	27.4% ($p = 0.195$)
Gastroenterology	-61.43% ($p < 0.001$)	-80.62% ($p < 0.001$)	30.47% ($p = 0.172$)
General medicine	-56.43% ($p < 0.001$)	-67.11% ($p < 0.001$)	16.92% ($p = 0.369$)
Breast surgery	-62.76% ($p < 0.001$)	-72.31% ($p < 0.001$)	15.36% ($p = 0.412$)
Neurology	-54.59% ($p < 0.001$)	-77.16% ($p < 0.001$)	9.45% ($p = 0.639$)
Physiotherapy	-58.13% ($p < 0.001$)	-84.36% ($p < 0.001$)	32.74% ($p = 0.134$)
Colorectal surgery	-60.44% ($p < 0.001$)	-80.64% ($p < 0.001$)	16.41% ($p = 0.319$)
Vascular surgery	-51.41% ($p < 0.001$)	-73.85% ($p < 0.001$)	4.99% ($p = 0.762$)
Rheumatology	-57.94% ($p < 0.001$)	-74.5% ($p < 0.001$)	13.82 ($p = 0.450$)

Discussion

Overall, our study shows that a large share of the unpaid carers cohort consists of a more vulnerable part of the population – older females from deprived areas on average. This population initially was more likely to have poor health before they were identified as carers in the healthcare system, and their health deteriorates faster, as unpaid carers have higher rates of certain long-term conditions like diabetes, hypertension and depression as well as higher frailty and lower PAM score. Poorer health is most likely the reason why unpaid carers have increased healthcare utilisation both in acute and planned services compared with non-carers.

Demographic analysis shows that the majority of unpaid carers are women, and the gender gap is particularly big in younger age groups. This is consistent with other studies and creates a strong incentive to address this inequality by developing policies supporting women providing care for others [7].

Another identified inequality is that more unpaid carers live in deprived areas, which means that socio-economic pressures are combined with additional caring responsibilities. Importantly, people in deprived areas become unpaid carers more often and at a younger age, which aligns to the overall poorer health and healthcare access in families from deprived areas [8].

Interestingly, there are more unpaid carers in Harrow than expected based on the proportion of the NWL population it represents. It would be interesting to study further whether this is related to an increased effort from GP practices to identify unpaid carers, or support from local authorities, or whether there are underlying reasons like specific deprived areas that drive this difference.

We also looked at healthcare utilisation by unpaid carers over time, aiming to understand the effect of the COVID-19 pandemic. We did not find significant changes in A&E rates. However, there is a decrease in usage of GP services after the pandemic started as well as fewer prescriptions issued. This might reflect higher healthcare system load as well as increased caring responsibilities, leaving less time for selfcare.

It is important to note that our analysis of the carers cohort's health before they were identified as unpaid carers, shows much poorer health across all studied long-term health conditions. Future unpaid carers are more likely to have complex health needs, including several long-term health conditions simultaneously. Since both carer and non-carer cohorts were matched, it is not likely that IMD, age or gender differences determine this effect, which requires further investigation. One possibility is that carers with poorer health interact with the healthcare system more, and therefore are more likely to have their unpaid carer status recorded through SNOMED codes. When speaking to unpaid carers, many mentioned they hadn't thought to inform their own GP that they were a carer. Many didn't see themselves as carers, initially. Some had been caring for years without mentioning it. Some GPs only became aware when the carer was visiting them with an ailment or condition related to their caring role.

The poorer initial health and higher prevalence of multiple long-term conditions aligns with the finding that unpaid carers have more than 2.5x higher odds of being moderately or severely frail. A complication with the eFI measurements is that each of its component deficits has a date, and these dates often span many years, so part of the unpaid carers cohort might get an eFI assessment before they were identified as a carer.

We showed also that the odds of having a PAM score of 50 or above is 22% lower for unpaid carers. The choice of such threshold for PAM score was determined by the selection of a model with better diagnostic metrics. However, a PAM score of 50 or above is consistent with the interpretation that such patients do understand their role in the self-care process, though they may lack some knowledge and confidence. This result may reflect the lack of time for self-care for unpaid carers overwhelmed with various types of responsibilities.

We did find a statistically significant but small effect (1% increase) of being a carer on BMI, which suggests that the metabolic health of unpaid carers is less affected than other aspects of health. This is contradicted, however, with higher rates of diabetes (see below).

Our age-sex standardised rates and long-term condition regression analysis indicate that carers are more likely to develop a wide range of long-term conditions after becoming an unpaid carer. These results resonated strongly in one of our public involvement workshops in which some unpaid carers highlighted that they often prioritise the health of the person they are looking after to the detriment of their own. One of the most distinct results is that of the increase in likelihood of developing a learning disability. The NHS includes a list of several conditions that fall into two categories, those that will indicate a learning disability, and those that may indicate a learning disability [9]. More research is needed to further clarify the effects of unpaid carer work in the development of learning disabilities. However, since the unpaid carers cohort had initially poorer health, we need to interpret the health effects of being a carer with caution.

Importantly, we found that unpaid carers use healthcare services more often than non-carers. There are two opposite effects that drive the usage of healthcare in unpaid carers. On the one hand, they have less time to utilise the healthcare system. On the other hand, as they have poorer health and potentially more understanding of the health system and how to access it, one may expect to see a higher demand for healthcare services. However, the fact that unpaid carers have a 16% increase in the rate of outpatient visits and a 57% higher rate of GP visits suggests that they still find time to address their increased healthcare needs, at least partly. Some works show, however, that GP service utilisation changes among carers are gender specific [10]. Further investigation is required to understand to what extent the increased demand for healthcare services is actually met for unpaid carers.

Our analysis of referrals by specialty also provided additional insights as to potential health inequalities that may have happened as a consequence of the COVID-19 pandemic. Our analysis identified a similar trend across referrals for all specialities included in the analysis. We identified a significant differences between the number of referrals between unpaid carers and non-carers, however the COVID-19 pandemic did not seem to further increase this difference. Furthermore, for all specialities, we identified a significant drop in referrals across all specialities when COVID-19 pandemic started. Through PPIE work, unpaid carers mentioned that carer responsibilities, lack of support, lack of time for selfcare, and financial hardship. increases stress levels, poor mental health and can impact physical health. For example, one carer mentioned they do lots of lifting of their husband, who has physical disabilities, which has led to chronic back pain.

"It's really, really hard… I'm more likely to suffer poorer health than my friends…I'm not having enough support."

The unpaid carers we spoke to, suggest several areas of further research and need for change. For example, many reported economic strains and a lack of financial support for unpaid carers, some of whom had to leave their jobs, due to their caring responsibilities.

They mentioned a lack of understanding from the organisations they work for or government about needing to take extra leave for care responsibilities or respite. They also noted that they wanted more joined up or integrated care. They said the system is fragmented and difficult for them to navigate, even though they have lots of interactions with care. Unpaid carers were appreciative of the support from charities and support groups like Carers UK.

> *"Everything is difficult, it is like harassment for us both to try and solve the system"*

In conclusion, our report finds significantly differing health status and utilisation for unpaid carers and provides the basis for important future research to better understand this population.

Limitations

Identification of carers using SNOMED codes

In this study we used the list of SNOMED codes recently published for identification of unpaid carers. However, different GP practices have different policies about coding patients. Also, GPs may not always identify carers or they may use a SNOMED code not listed in the recommendations. Through PPIE activities, several carers mentioned that they had not mentioned to their own GP that they were caring for someone else, although they are encouraged to do so by support groups and at the Carers Assessment. Other studies have reported that men are less likely to have interaction with their GPs [13], so it is possible that this method of identifying unpaid carers may not perform as well when identifying male unpaid carers. It is worth noting that timing of carer registration with a GP is usually not an accurate marker of when someone actually becomes a carer. It may explain why carers cohort have much poorer health compared with matched cohort at the time of carer registration.

Duration of unpaid carers code
It is not possible to reliably identify the duration of caring responsibilities using SNOMED codes as SNOMED codes referring to stopping being a carer may not be used consistently.

Identification of long-term conditions
It is important to take into account that for most conditions, the timing of a SNOMED code also isn't equivalent to when the condition started.

No flags for patients who have left NWL
The Discover dataset does not have flags showing patients who have left NWL, and therefore the numbers of patients in the cohort can be overestimated.

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