

Unpaid Carers in Leeds

NDL Leeds, NHS West Yorkshire ICB

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How much to we know about unpaid carers in Leeds?

The Parliamentary Family Resources Survey (2021) estimated that in 2019/20 around 7% of the UK population were providing unpaid care, although their definition is 'informal care'. Similarly, the Carer's Week Research Report (2020) estimated that around 1 in 4 people in the UK could be providing some level of unpaid care, with around 74,000 estimated unpaid carers in the Leeds City area (2011 Census/Carers Leeds, 2020).

The needs of unpaid carers are known to be complex and varied, with surveys finding that around 83% of respondents reported a negative impact of caring on their physical health, and 87% responding negative impacts on their mental health (In Sickness and in Health, 2012). With so many people providing care across Leeds and such high levels of reported needs nationally, it is important to investigate the full health and social-care needs across Leeds, and identify potential gaps and inequalities in service use.

The Leeds NDL team has conducted and commissioned research to establish gaps in the knowledge of both the Leeds population, the ICB in Leeds/Leeds City Council teams regarding the needs of unpaid carers, and the utilisation of services by unpaid carers. A Task and Finish group comprised of professionals (council and third sector) who work with and on behalf of unpaid carers, and unpaid carers from different economic and ethnic backgrounds was set up to find the commonest problems encountered by carers, defining the questions which we investigated.

Available Data

Our primary sources of data used to identify carers for this investigation were:

- **Primary Care records**, coming from GP appointments or registrations, where a clinician or Practice employee noted that a patient was an unpaid carer,
- **Adult Social Care records (from CIS)**, marking contacts between people and the council, as well as Carer's Assessments (singular and joint), sign-posting to third sector carer's services, and direct packages of aid for both carers and cared-for people.

As well as this, we also had access to **Secondary Care records**, including inpatient appointments (elective/non-elective), and emergency attendances at A&E.

An interactive version of this report can be found here (<https://ben-alcock.shinyapps.io/project-3-scrollly/>).

What demographic variation do we have in our GP carers data?

In the 2011 census around 11.2% of people (age-standardised) recorded that they provided some level of care, while this level had dropped to 8.7% at the 2021 census. If we look at data from the past five years, we find around 19,000 patients who have informed their GP of their caring status: around 25% of the expected number. If we limit our time-window further, and only look for carer registrations within one year then we find between 6000-10,000 patients looking back for each year from 2016-2021: an average of around 10% of the expected count.

Based on interactions with GP practices, common population health findings, and anecdotal feedback from the Task and Finish group, we would not expect this underrepresentation to be found equally across all demographic groups across the city, and so we compared our GP carer data with ONS mid-year population estimates to highlight the specific groups which feature fewer registered carers.

Here, we look at the proportion of the population which has registered as a carer, split by year and demographic information (age-band, sex, deprivation level). We calculate population proportions by using GP records for all registered Leeds patients who live within the Leeds City Council boundaries, and compare these figures to the ONS population estimates for the same areas.

In every year, the population proportion of carers falls well short of the expected figure from the census results. Prior to 2020 we can see a slight increase in the proportion of registered patients providing care, rising from around 1.08% in 2016 to 1.70% in 2019. We see a large increase in 2020 (up to 2.2% of the population), before dropping to around 1.45% in 2021.

Splitting by patient sex, in all years we see significantly more female carers than male carers, with roughly double the proportion of the female population registering as carers than the male population (allowing for some variation).

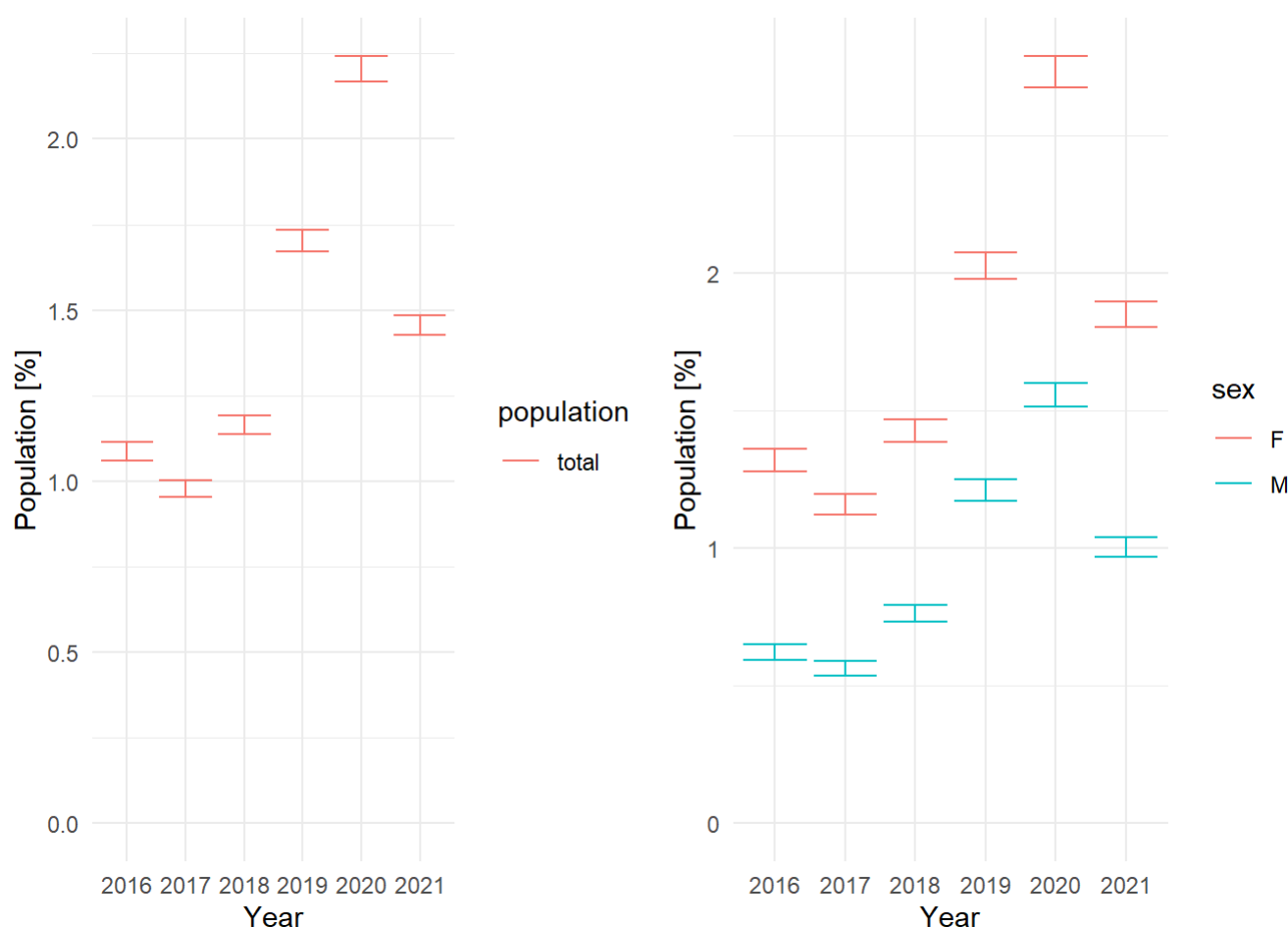
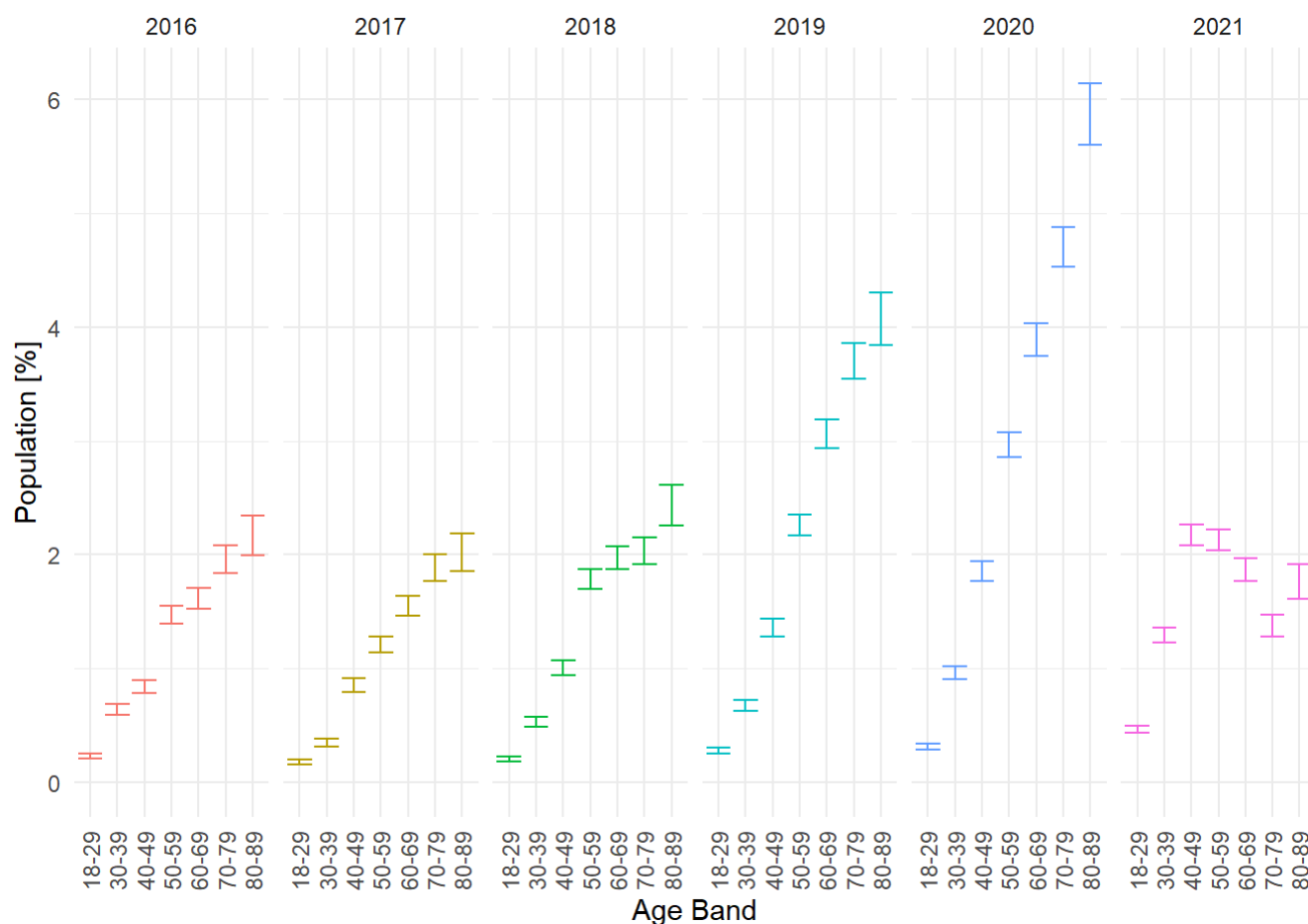


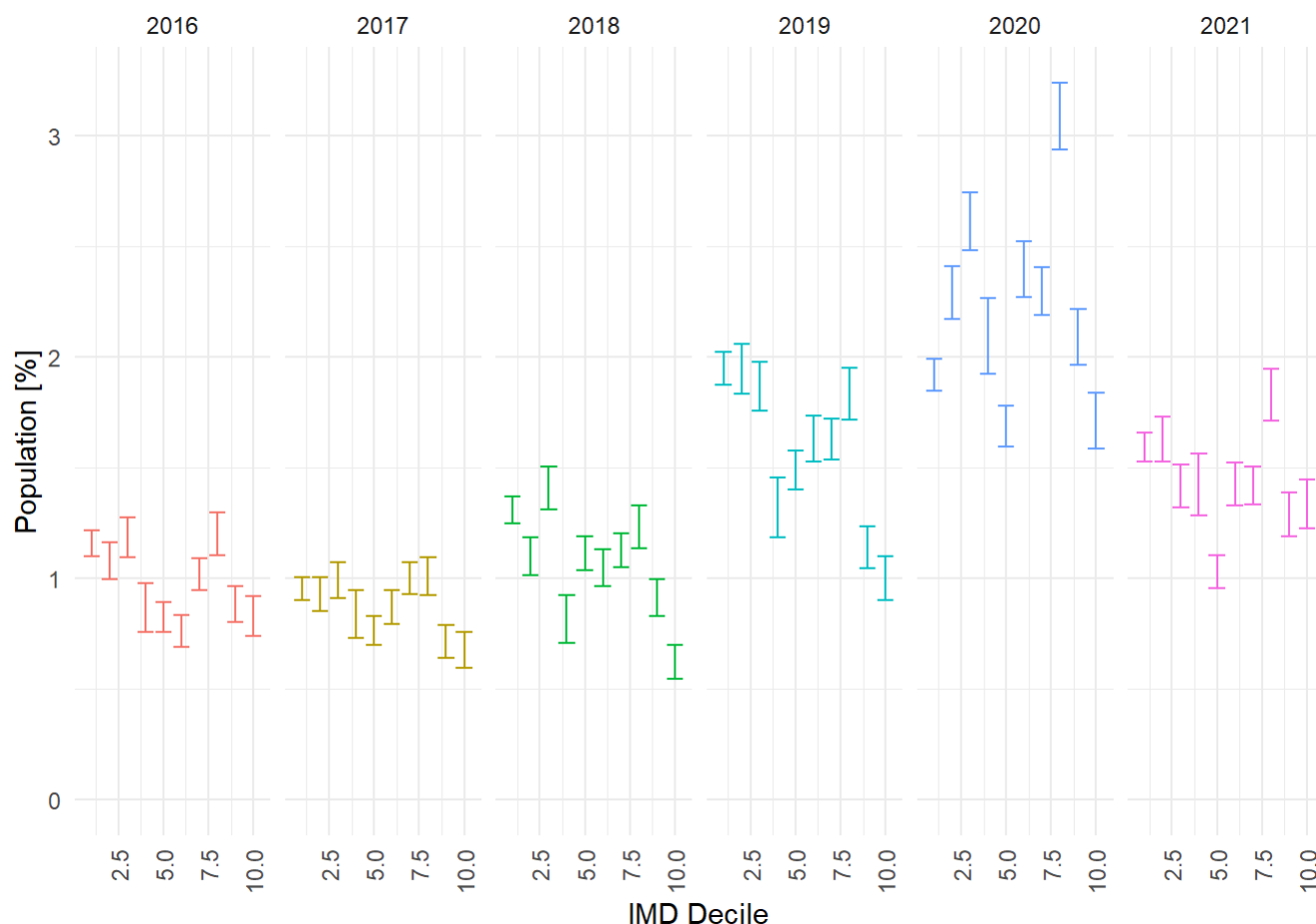
Figure 1: The number of GP registered carers as a proportion of total Leeds population (18+) (a) and the number of male and female GP registered carers as a proportion total males and females in Leeds (b)

When we split patients by age band we see the largest differences in registration proportions. Pre-COVID, we see a roughly linear increase in the proportion of carers with ten year age-band. However, the population proportion difference is not static, with increasingly greater numbers of older carers registering than younger carers. In 2016, there were approximately 9 times more elderly (80-89) carers than younger (18-29) carers, but by 2019 this difference had increased to around 14 times. During COVID (in 2020) this difference rose to nearly 19 times more elderly than younger carers, however this difference dropped off in 2021, with fewer elderly carers registering, but higher numbers of younger - middle-aged carers.



Interestingly, there is no consistent strong trend observed with deprivation level - proportionally people who live in the most deprived areas in Leeds are roughly as likely to tell their GP that they are a carer as those who live in the least deprived areas.

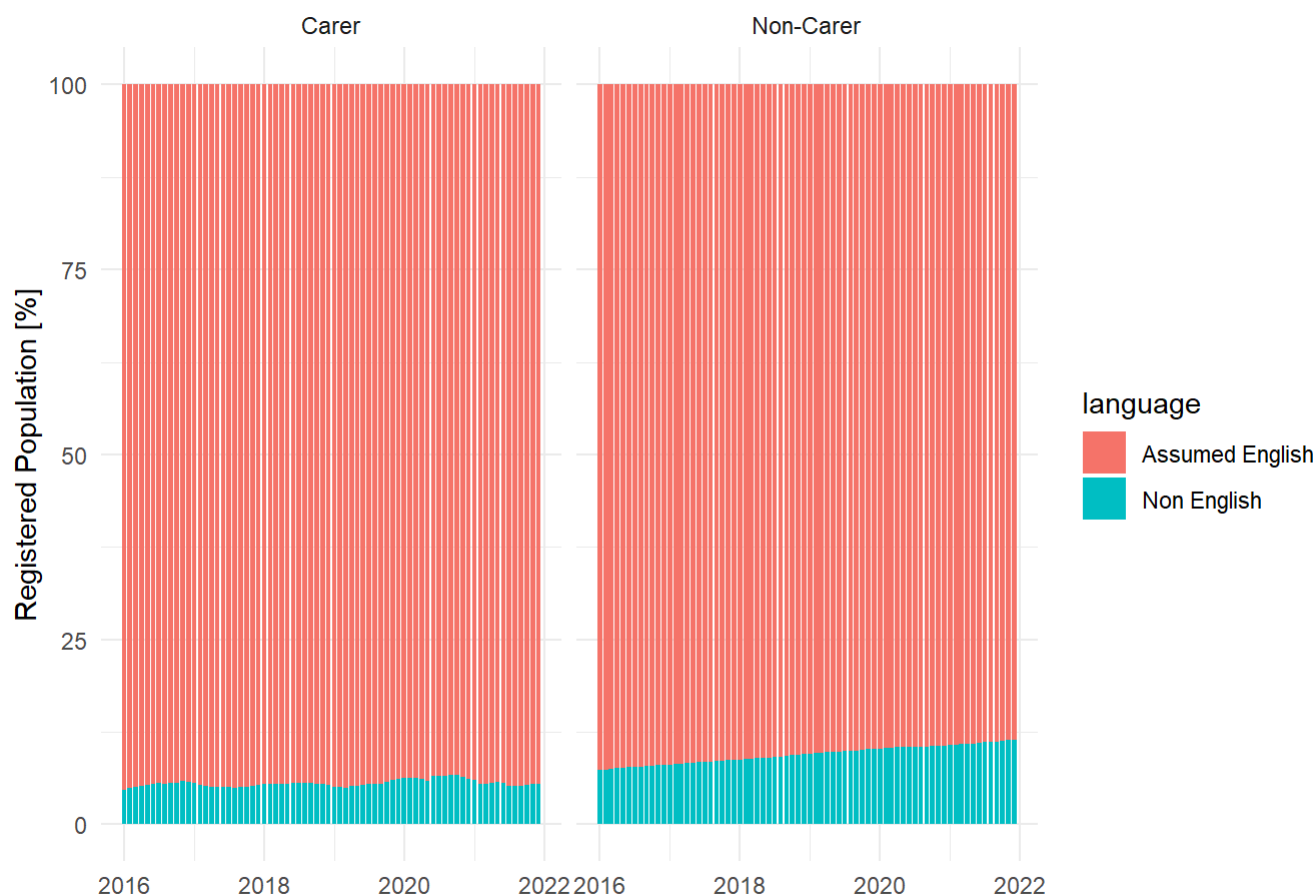
Based upon the health-needs of the city, it is known that people who live in the most deprived areas generally feature poorer health outcomes (higher levels of chronic illness, lower life expectancy, and lower healthy life expectancy), and so it could be assumed that people from these areas would also be more likely to provide care for a family member or friend. However, as described above, this is not seen in the GP carer registrations - potentially pointing towards a lack of registration among areas of higher deprivation.



For the remaining demographic descriptors (ethnic background and first language) there were no population estimates available per year, and so our cohort changed slightly to all registered patients. Our numerator and denominators came both from GP registered patients, with flags for language and ethnicity pulled from GP records. The proportion of people with certain flags was then compared with the full GP population, split by registered carer/non-registered carer status.

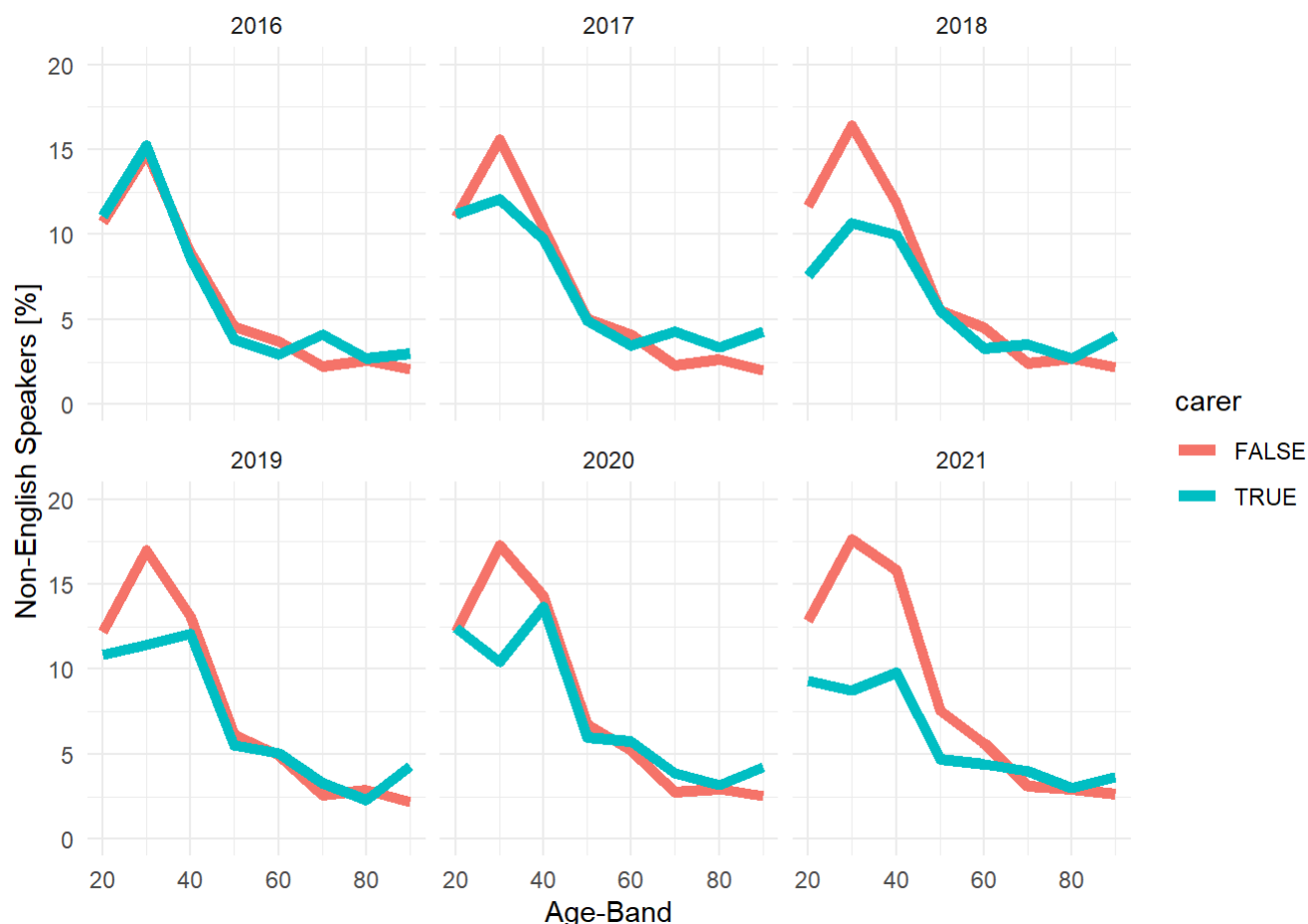
Overall in Leeds around 85% of patients have had their primary language recorded by their GP. For the total population the proportion of English speakers has dropped from around 77% in 2016 to 73% in 2021. However, the proportion of carers who speak English as their first language is significantly higher at all times: at 87% in 2016 and 85% in 2021.

Similarly, the proportion of non-English first language patients is significantly lower amongst the carer cohort than the non-carer cohort (5% vs 7% in 2016), and the carer cohort experiences little overall change compared with the non-carer cohort (5% vs 11% in 2021).



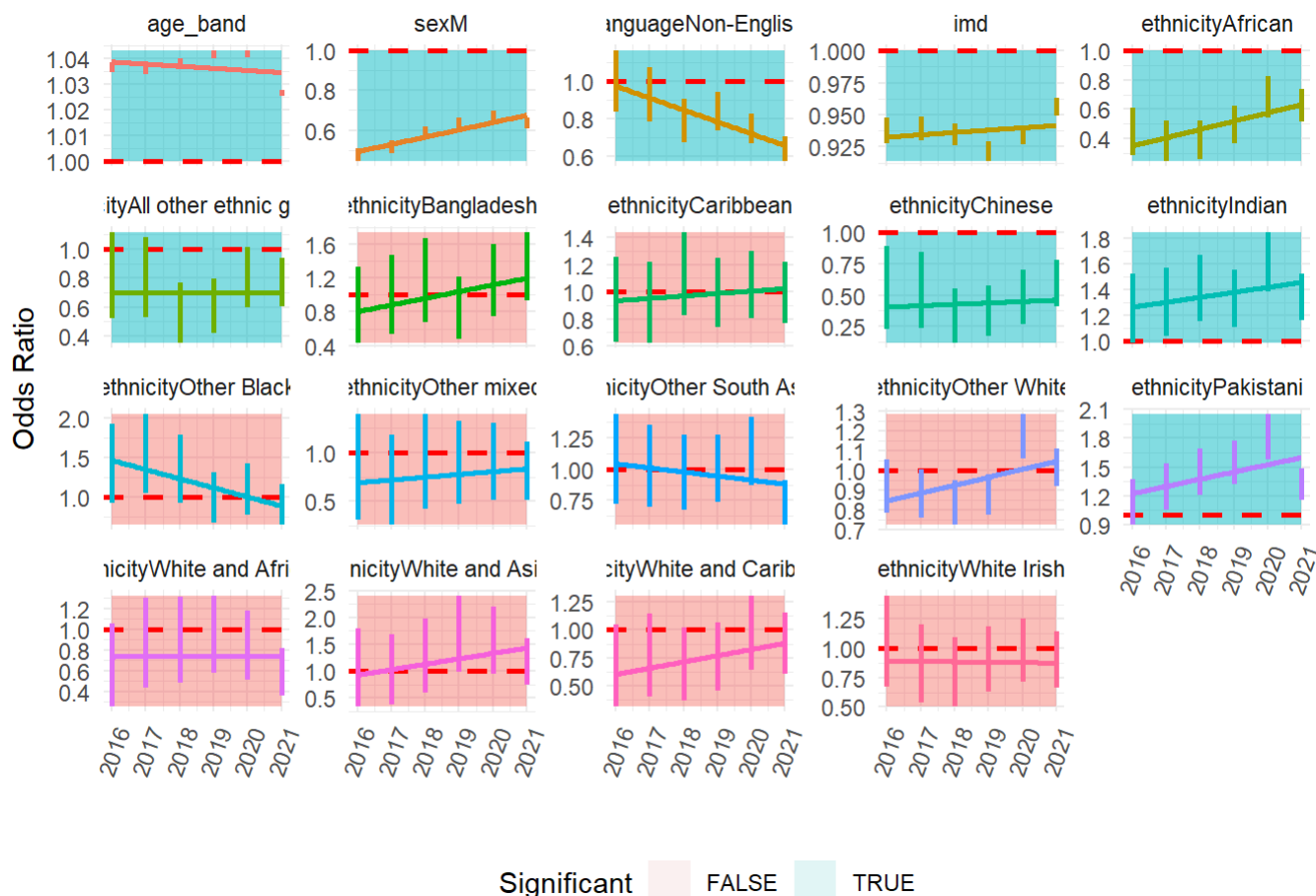
It is likely that a significant portion of the apparent under-representation of non-English carer registrations arises as a result of the difference in average age of non-English speakers, as across Leeds the older the group, the more likely the person is to be a primary English speaker. We know that most carer registrations come from the older age groups, so we need to account for patient age when computing rates of non-English speaking groups.

When we split by age-band this assumption is partially confirmed - at the higher age-bands we see roughly matching proportions of non-English speaking patients for both carers and non-carers. However, while the younger age-bands broadly matched carer/non-carer proportions in 2016 we can see a divergence over time, with proportionally fewer non-English speaking patients registering as carers over time. At its greatest extent, we can see a large difference for 20-40 year olds across Leeds, with far fewer non-English speaking carers than would be expected when accounting for age differences.



To estimate the effect of each demographic variable on carer registration rates, we ran a binomial GLM, predicting whether a patient would register as a carer based upon their age band, sex, main language (assuming unknowns were English-speaking), residential deprivation decile, and ethnicity group. From this model, odds ratios were calculated. Note that these were based upon GP data, so outcomes will have slight deviances when compared with ONS population estimate data.

Of note, we can see that age is a consistently significant indicator of carer registration, with each year increasing a patient's odds of registering by around 3-4%. Similarly, we can see that as we already found, men tended to have 40-50% reduced odds of registering compared with women, although this has been slightly decreasing since 2016. Deprivation has a significant, although relatively smaller, effect, with each deprivation decile featuring around a 5% decrease in odds of registration, and as we have seen language in 2016 had little effect, although by 2021 this has grown to around a 30-40% decrease in registration odds for non-English first language patients. Finally looking at patient ethnicity registration rates (compared to 'White British' rates), we can see that, despite having generally younger age-distributions, Indian and Pakistani patients are around 5-20% more likely to register as carers than White British patients, while Chinese and African patients are significantly less likely (50% and 40% respectively). In all significant cases, we can see an upwards trend - with odds of registering compared with White British patients generally increasing over time, although the specific rate of increase varies greatly across different groups.



Carer Registrations

Next, we were interested in looking at seasonal variations of carer registrations at GP practices. We split these between 'pre-COVID' (2016-2019) and COVID (2020-2021), and in both were interested in looking into the demographic differences of people who registered within those times. Pre-COVID we were particularly interested in looking at pre-retirement age registrations at first, as these are likely to vary significantly when compared with retirement-age patients (70+). During the COVID pandemic we were interested in both working-age registrations and retirement-age registrations.

Pre-COVID

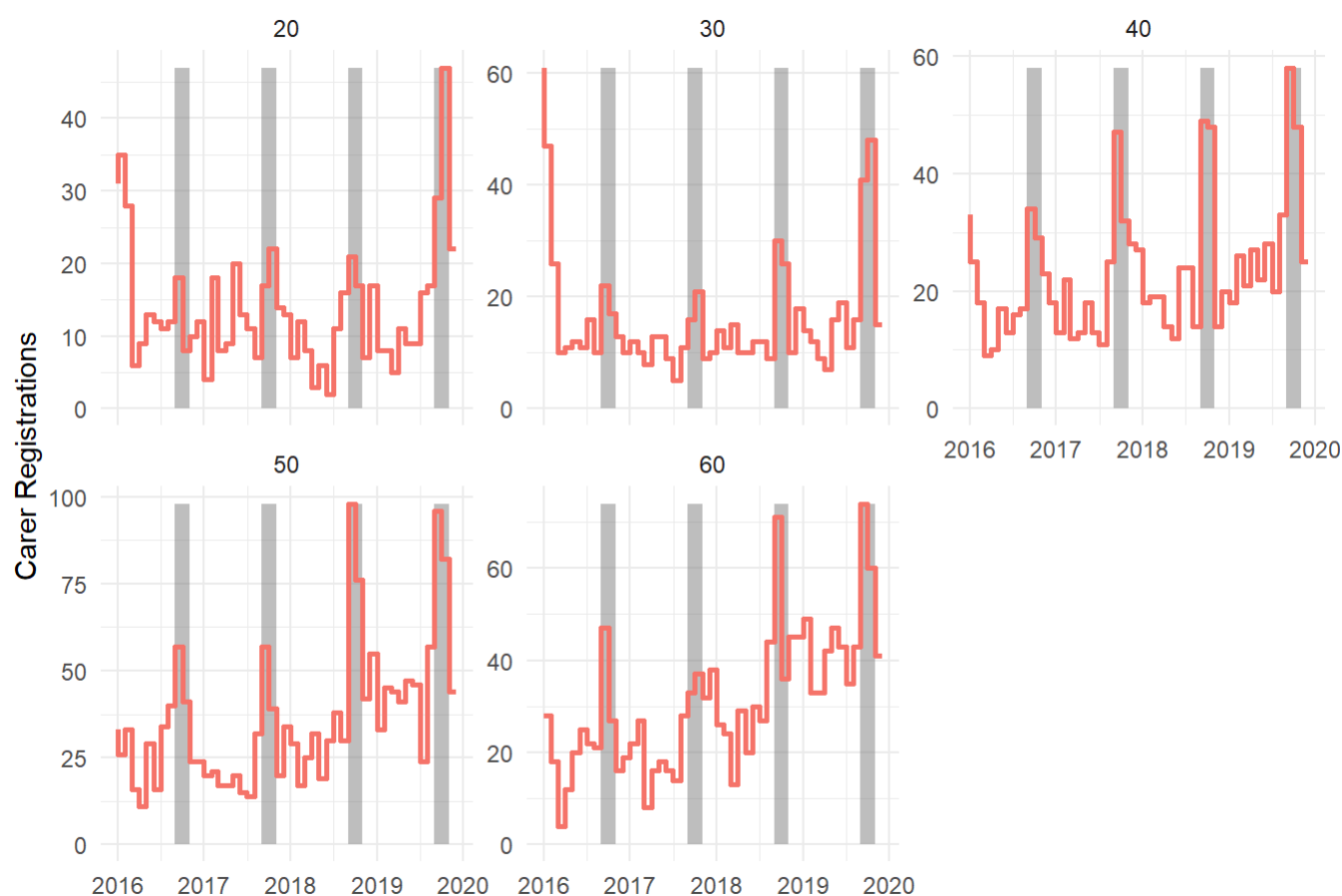
Pre-COVID, by splitting registrations by 10 year age-band, we can clearly see waves of carer registrations in all age-bands except the 20-year old band. These generally occur in the Autumn (September - November), corresponding well with usual vaccine drives for flu vaccines, which would usually not be available freely for working-age adults. As part of our engagement with health and social care professionals, we discussed the benefits of registering as a carer with a GP practice, and one of the key messages was access to vaccines, such as for flu or COVID. Clearly from this it could be inferred that the vaccine drives had a good impact on carer registrations - either for encouraging carers to register with their GP, or for encouraging GPs to discuss patients' caring responsibilities in the lead up to vaccinations.

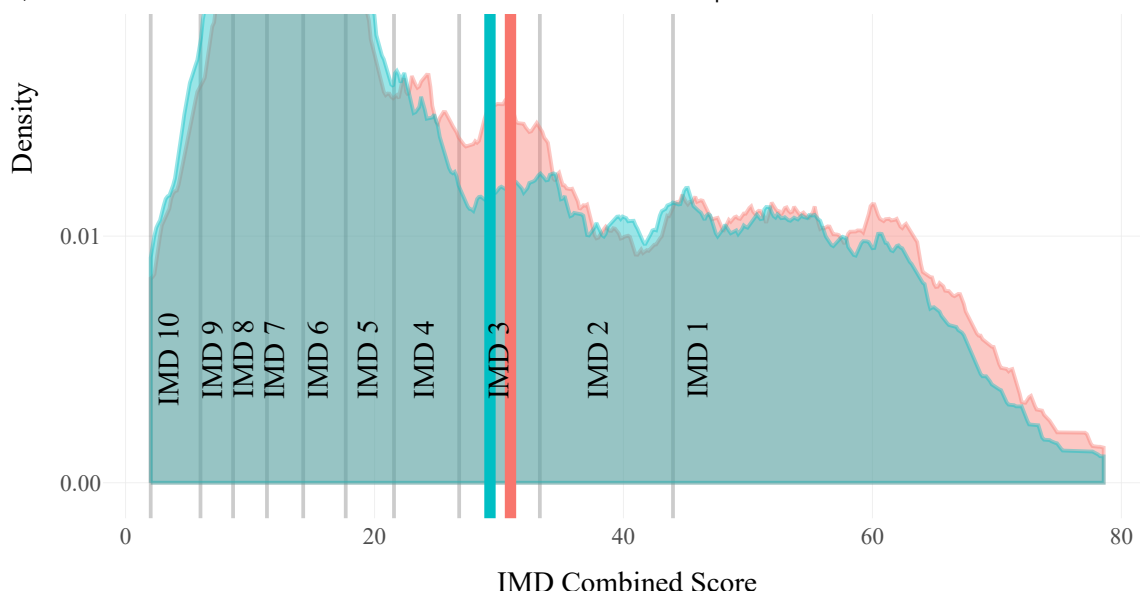
However, while the base numbers of carers can be seen to increase seasonally, we were also interested in

looking at the groups which benefitted from this, to see if these vaccine drives were effective at drawing people from different demographic backgrounds to register. To investigate further, we took each registration and added a flag if it occurred within the marked (signal) times, shown here for registrations from the 60-69 age group. Based upon this we looked particularly at the deprivation levels of the areas from which carers lived.

Looking at the whole population, we took the combined IMD score for each area and looked at the change in deprivation level for patients who registered as carers during our signal times to those who registered outside these times. Here, an average shift to higher scores would mean that a greater proportion of patients from more deprived areas register as carers during the signal periods, while a shift to lower scores would mean the inverse.

We observed a statistically significant shift ($p = 0.0015$) to lower deprivation levels, signifying that during our signal periods people from less deprived areas were more likely to register as carers at their GP practices than those from more deprived areas. This shift was also significant for female patient registrations, and for younger age bands, although not for male patients or older age-bands. Significance was gauged via Mann-Whitney U tests.



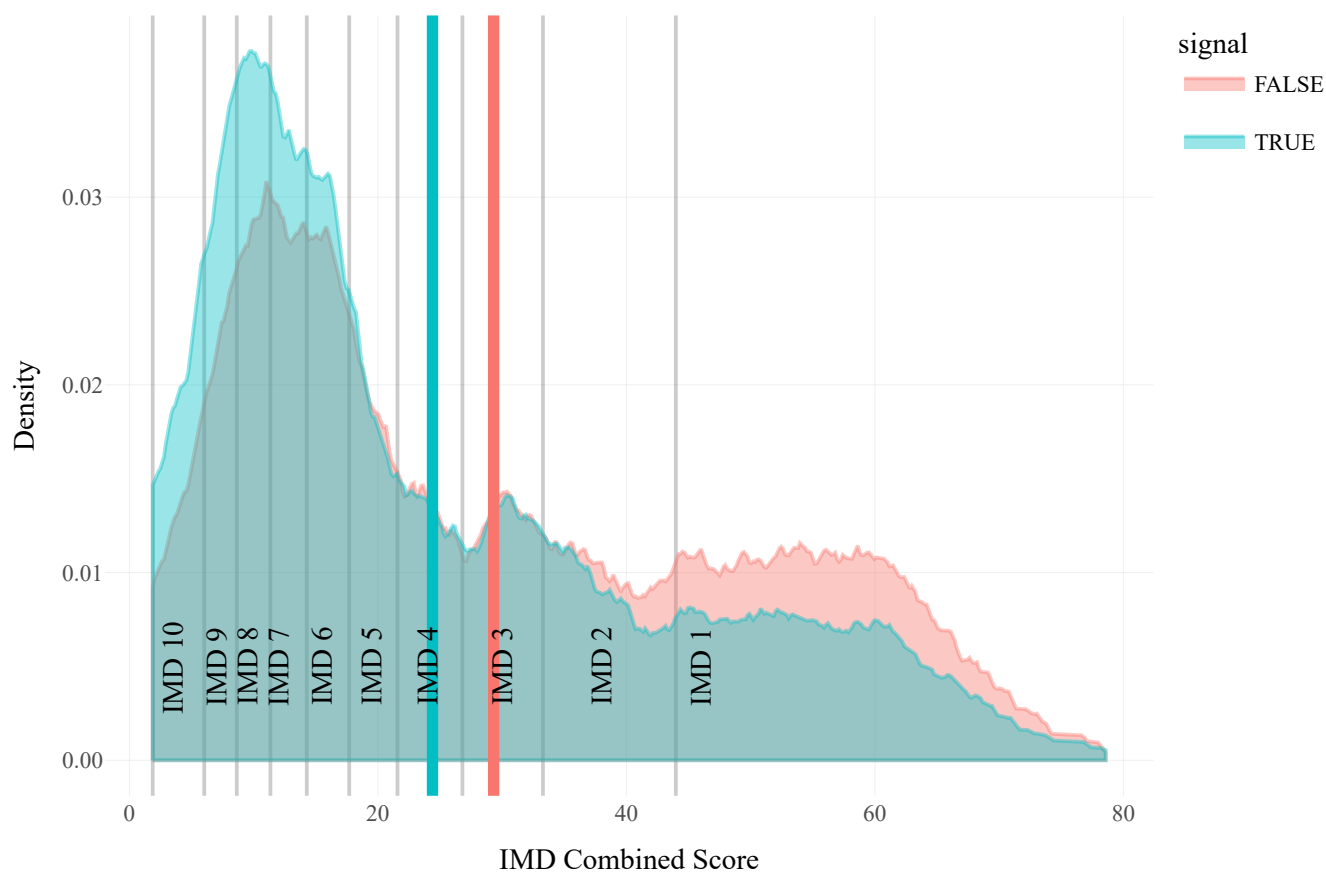


COVID

Moving to 2020 and extending out our analysis to cover all adult age-bands, we repeated the above method to compare peak times of interest to 'usual' background registrations levels. However, as COVID occurred in 2020 and the COVID vaccination started at the end of 2020 we shift the focus from autumnal vaccinations to focus instead on the period where the first wave of COVID hit the UK (around March-May 2020) and the period where vaccinations began in earnest (around January-March 2021).

The COVID pandemic had a significant effect on carer registrations with higher rates of registration across all age bands. For working age patients the largest effect was seen around the beginning of 2021, when the vaccine rollout began, with carers receiving vaccines sooner than normal for their age band. For older carers there was little-to-no change in registration rates in the same period, likely due to 70+ patients receiving vaccines early regardless of whether they were carers or not. However, there is a large spike in registrations for these age bands at the beginning of the pandemic (March-May 2020), when clinically extremely vulnerable patients (who may have had care-requirements) were advised to shield, and an identification programme was rolled out nationally and in GP practices.

Repeating the same method as above to compare the deprivation levels of areas in which patients who registered during signal times to patients who registered in 'usual' times, we can see the same pattern but at much greater levels - during these drives it was more often patients from less deprived areas who were identified at GP practices as carers, a finding which again holds true over the whole population ($p < .0001$), and when split by sex (M: $p < .0001$; F: $p < .0001$) and age-band (20-50: $p < .0001$; 60-80: $p < .01$; 90: $p = 0.2$).



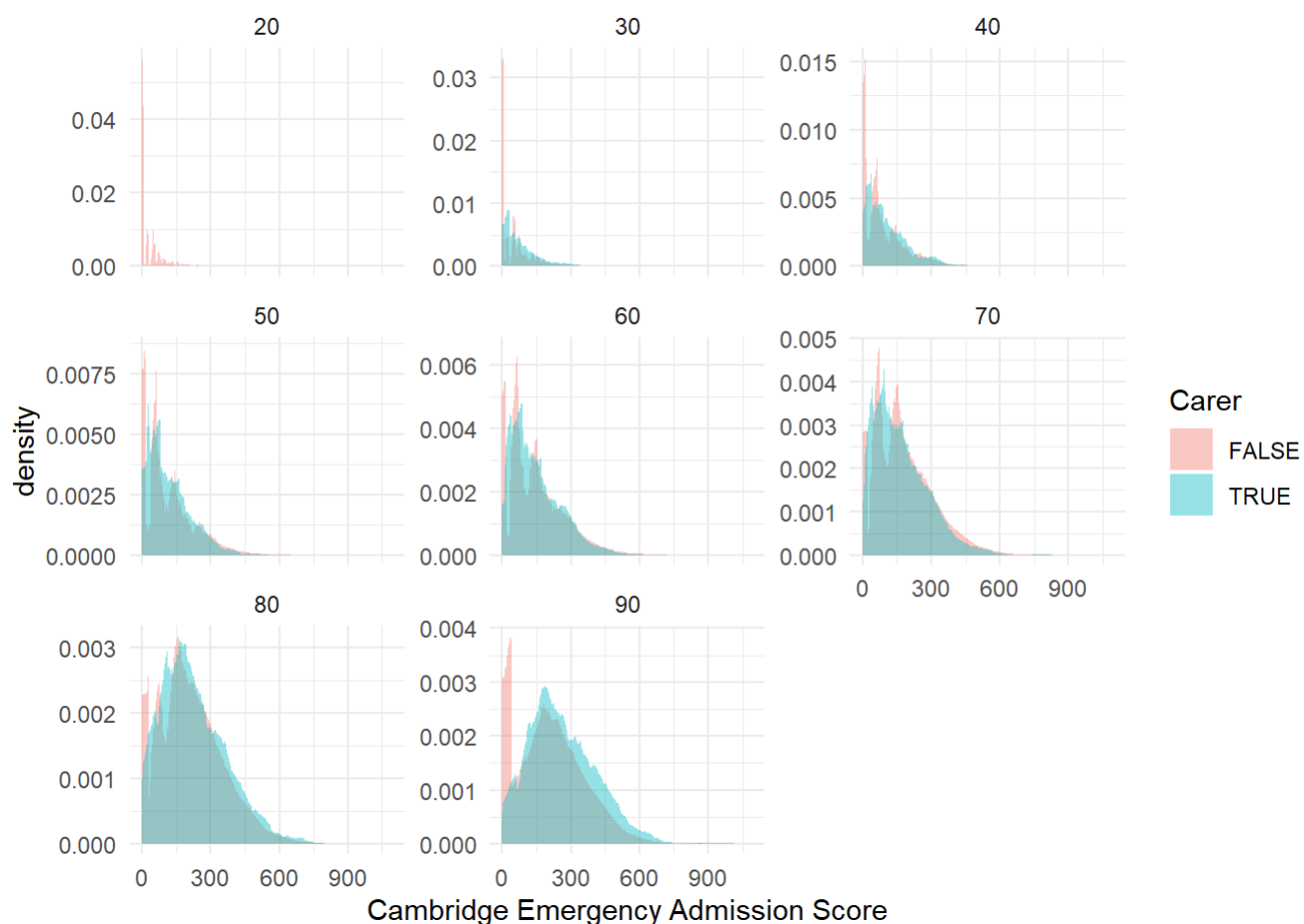
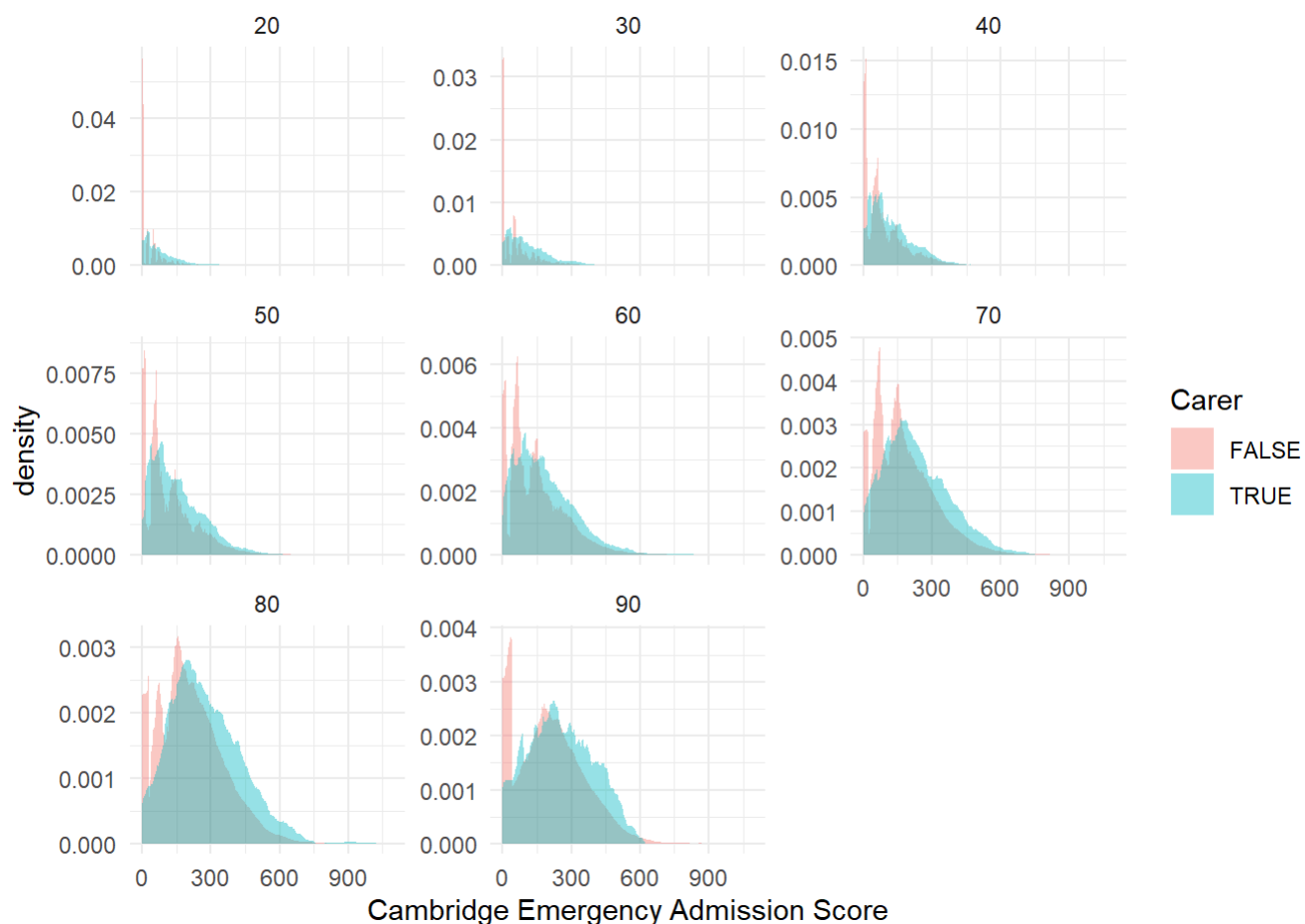
How does the health of registered carers compare with non-carers?

As discussed above, in surveys carers have reported that caring has negative impacts on both their physical and mental health, and as such it could be expected that the prevalence of chronic health conditions would be significantly higher amongst carers than non-carers, when accounting for age and sex differences.

To test this, for each patient in Leeds we combined data from historic GP appointments, including information about medication prescribing and clinical diagnoses. To estimate each patient's health need, we calculated their Cambridge Multimorbidity Score (CMS; Payne et al. 2020). This was done by searching for 37 specific conditions (including many QOF conditions) and, for each condition, if a patient reached a certain criteria (such as '*condition ever recorded*', or '*4 or more specific prescriptions within the past 12 months*') then a flag for each condition was listed. For each met condition we took the 'Unplanned Admission' weights calculated by Payne et al., which estimates the risk of a patient having an unplanned hospital admission within the next year, and added the risk scores together to estimate a total unplanned admission risk.

When splitting by age-band and comparing the distribution of risk scores, in all ages we can see that registered carers generally have higher scores, meaning that on average registered carers would have higher health needs than a similarly aged non-registered carer. However, it can be seen that patient risk score also generally increases with age, meaning that registered carers tend to match more closely in risk score with patients a number of years older than themselves. For this, we were interested in seeing the age difference between carers and matching non carers, by looking at the CMS risk score distributions. We artificially increased carer ages and calculated the difference between carer and non-carer risk score distributions for each age-band (via Chi square goodness-of-fit). At each age-shift, the average Chi square was calculated, with the optimal shift being given by minimised average chi square. Groups with fewer than 100 carers were excluded from the calculation.

Using the goodness-of-fit calculation we found that the optimal age-shift of carers was 13 years - that is, when comparing different patients by using the CMS risk score carers in Leeds appear to match best with patients 13 years older than themselves. This method was repeated varying the size of the age-bands (from 5 years up to 20 years) and roughly the same optimal age-shift was found. This is shown for age-shifts of 0, and 13 years.



During our Task and Finish group meetings, many carers brought up anecdotes that they and other carers they know had cancelled hospital operations because of the recovery time, because they had no way of covering for their caring responsibilities. In the case above (where registered carers have more similar health characteristics

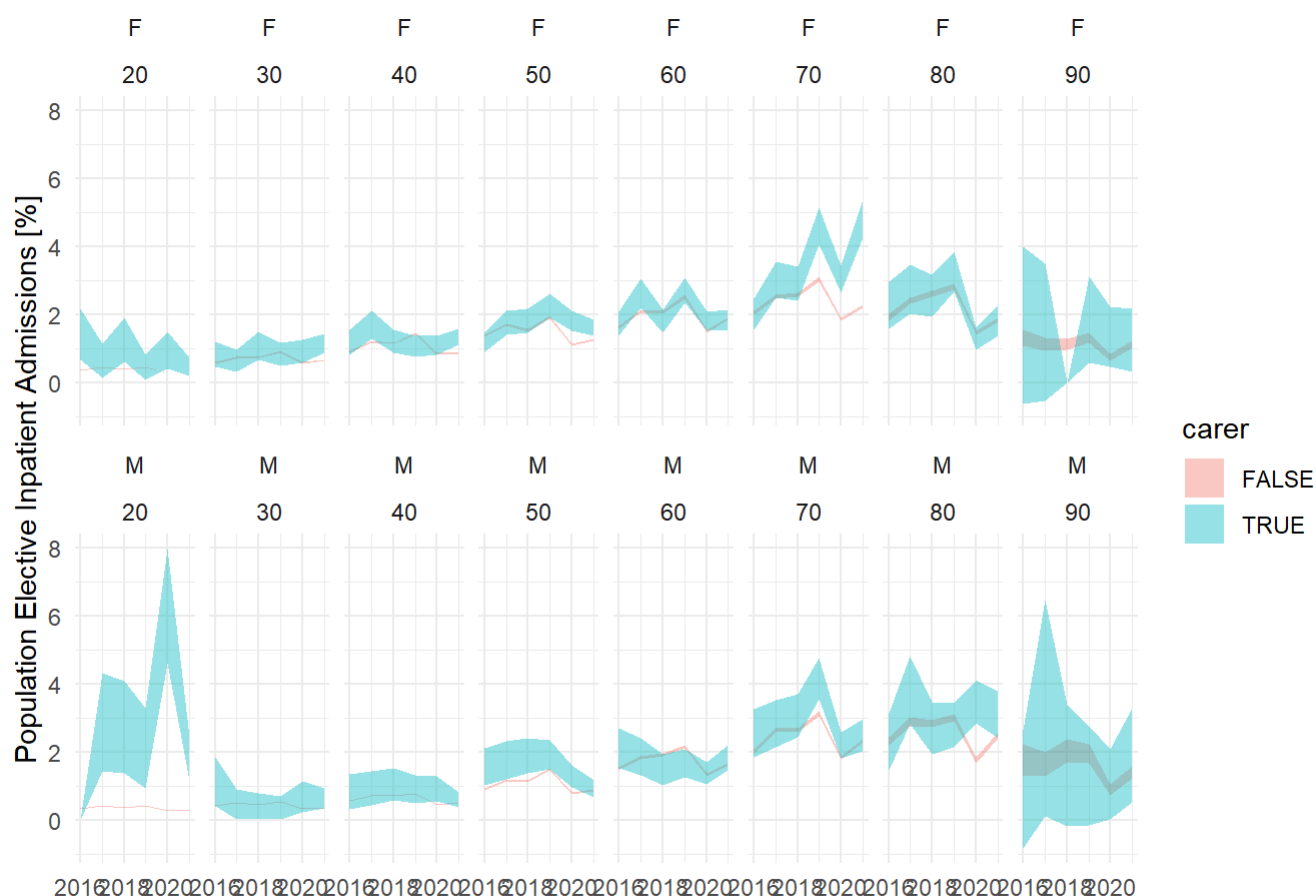
with people 10-15 years older than themselves) these anecdotes could explain the increased health risk of carers, due to a lack of maintenance of known conditions.

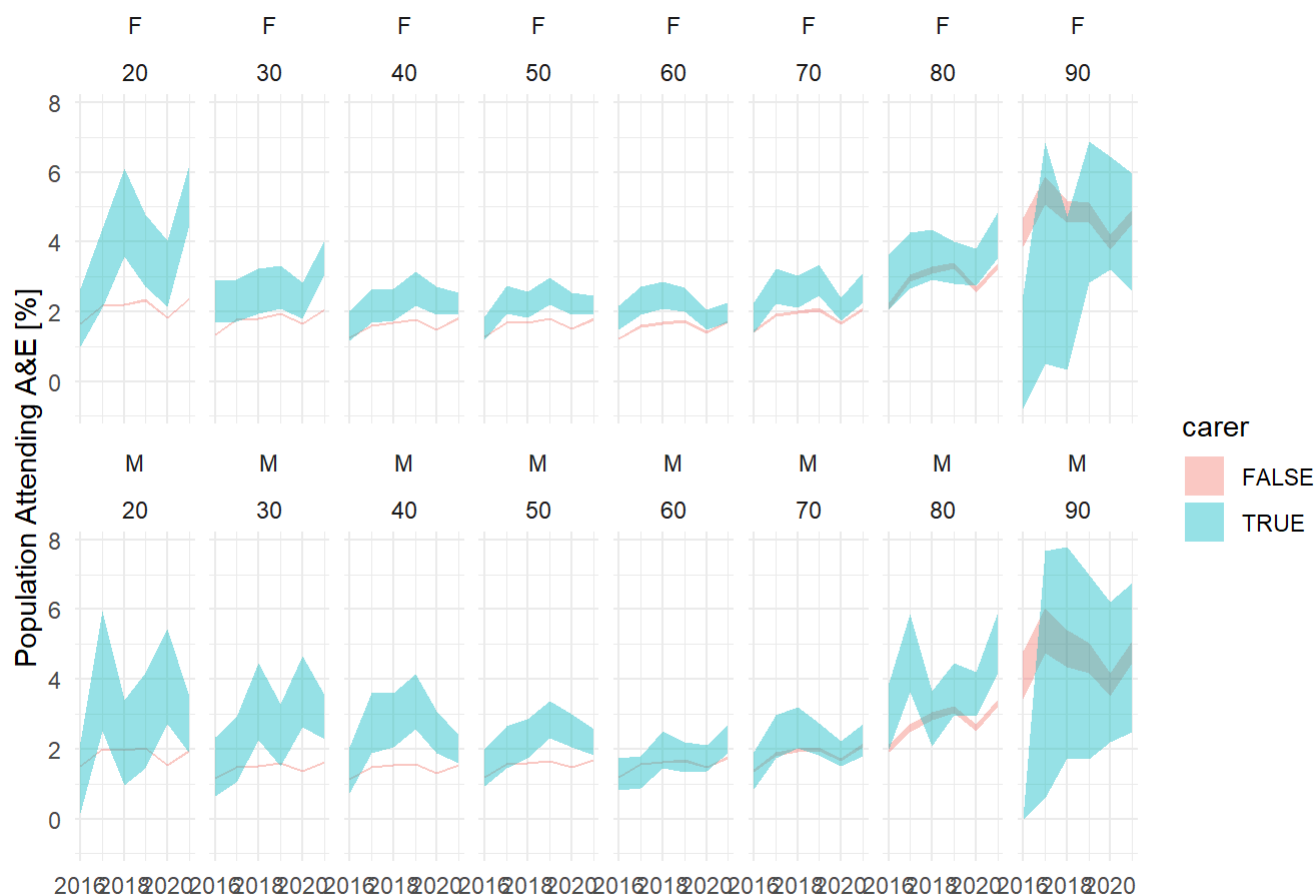
In the case of our T&F group, different experiences were discussed. One carer had conditions flagged at GP appointments which were not resolved with an elective operation, despite steady worsening over a number of years, resulting in a non-elective admission to hospital. Another carer discussed cancelling an operation which would have resolved chronic pain issues - resulting in no further hospitalisation but decreased quality of life.

Within our data set we do not have access to hospital bookings, and so were unable to directly compare the cancellation rates of carers and non-carers. However, as a proxy, we have been able to use SUS to compare population rates of elective inpatient admission to A&E attendances.

Interestingly, when we split the proportion of Leeds-registered patients who attended an elective inpatient spell (split by sex, age-band, and carer status), we generally find that registered carers are approximately as likely as non-registered carers.

However, when we look at the percentage of the population who attended A&E, we find that generally registered carers are more likely than non-registered carers to attend A&E, when split by sex and age-band. This increase is generally seen more in female patients than male, and for both male and female the biggest differences are seen around 40-59 year olds (although female 18-79 year olds near-consistently show this trend, whereas it is only really seen for male 30-59 year old patients).





Discussion and Conclusion

In this work we have looked at unpaid carers in Leeds, focussing on registration rates by GP practices and secondary care interactions. By using GP records it can be seen that registered carer rates have been generally increasing between 2016 and 2021, with particularly sharp increases in 2020, likely due to the COVID pandemic. However, proportionally it can be seen that registration rates are unequal across different demographic groups. The most significant shortfalls were: men were around 40-50% less likely than women to register as carers; younger people (18-39) 10-20 times less likely than retirement-age people (70+); non-english speaks 10-40% less likely than English speaks; and Chinese and Black/Black British people significantly less likely than White British people to register. Conversely, we have found that Indian and Pakistani patients are more likely than White British patients to register as carers. While some of these factors are well correlated (for example with Chinese patients being significantly younger than White British patients - clustered around University ages - and hence lower registration rates could be expected), some ratios go against these correlations, such as Indian and Pakistani patients who are generally younger than White British patients, but feature higher rates of registration. Further investigation is required to find out whether this is due to higher need (i.e. higher levels of unregistered carers) or better GP interactions due to interventions, or a combination of both.

Looking at carer registrations broken down by month, in most ages we can clearly see spikes - before COVID these generally occurred in the Autumn when flu vaccinations were occurring, and hence either GPs were more likely to record people as carers, or carers were more likely to contact their GPs. During the COVID pandemic this shifted and was split by age: retirement-age patients had a large increase in registrations at the beginning

of the pandemic when work was undertaken to identify critically extremely vulnerable patients (and hence their carers), while working-age patients had increased registrations at the onset of the vaccination drive, allowing them access to earlier vaccinations than would be otherwise allowed purely based upon their ages and known health conditions. On average, pre-COVID registration rates increased by 1.5-2 times during vaccine drives, and during COVID these increased further to 2-5.5 times.

However, while vaccine drives (and the shielding identification drive) have been very correlated with increased numbers of carer registrations, we find that these registrations occur more often from areas of lower deprivation and less often from areas of higher deprivation. Pre-COVID the effect was statistically significant, although small, for the full population deprivation shift, and was significant when looking at only female registrations and younger carer registrations (<40) - although no significant effect was seen in male registrations or older carer registrations. During the pandemic this effect increased, with both greater changes in the average deprivation score and more groups featuring statistically significant shifts.

These effects can be taken two ways - they show a clear and consistent trend that, during periods of increased call for carer registration, the numbers of carers registered increase greatly, suggesting that on the whole these drives are very successful in their aim. However, the pattern found for female and younger carers pre-COVID, and all carers during the pandemic, suggests that these drives are greatly more effective in areas of lower deprivation, where interactions with GP practices may be more routine. Future commissioning should look into specific cases to see whether more communications or engagement could benefit these drives, if targetted to areas of lower deprivation.

Finally, we considered the health needs of our registered carers. From the literature and through discussion with carers in our Task and Finish group, we know that carers tend to have poorer health outcomes than similar non-carers, and we learned of specific cases where carers put off their own health needs for that of the person they care for, worsening their health outcomes over time and in some cases resulting in longer spells in hospital than would have been required if they were able to act sooner.

We approached this in two methods - firstly, we looked at registered carer risk scores using the Cambridge Multimorbidity Score, and compared these to similar non-registered carers, splitting by sex and age-band. On comparison, we found that registered carers are more similar with non-registered carers 10-15 years older than themselves. However, presently it is unknown whether these patients' caring responsibilities has reduced their health outcomes (i.e. has caring aged them), or whether we only know about these carer because of their already increased health needs, which has put them in more contact with GPs and hence increased their chances of being recorded as a carer.

To investigate further, we next looked at hospital usage by registered carers and similar non-registered carers, comparing elective inpatient spells to A&E attendances. In theory, based upon carer stories, if carers tend to put off medical procedures until they progress to a point where they can't be ignored, we would expect to see lower (or similar) rates of elective attendance but increased rates of emergency attendance. When splitting by sex and age-band, this is what we find: registered carers have broadly similar rates of elective attendance at hospital, but significantly higher rates of attendance at A&E in most age-bands. While it is interesting that these registered carers have similar rates of elective admission to hospital, based upon their CMS scores we could have expected to find greater rates of admission - suggesting that the carer anecdotes of cancelling appointments due to any recovery time hold true for the full Leeds population.

Again, we are limited by the fact that we can only compare rates of carers *who have registered* to all other patients, and so future work will look into grouping patients into households by using a pseudo-household ID from TPP/SystemOne, and identifying 'probable carers' based upon the health-needs of the property. An example would be a four person household, with two adults and two children, where one adult has an SMI indicator, or an indicator for severely reduced mobility. Once a cohort of these patients has been found, the above methods will be used to compare both the CMS scores of 'probable carers' to registered carers, and

compare the elective admission/A&E attendance rates of the two groups. This will help identify where interventions would be best placed; if 'probable' carer demographics and history with GP practices broadly match those of registered carers then future commissioning should look into working more closely with GPs to help increase rates of carer registration. If the two groups are found to differ significantly in either demographics of healthcare-interactions, then more targetted interventions aimed at a community level should be investigated.