

NDL West Yorkshire ICB – Support for Unpaid Carers in Leeds

Summary:

The 2021 Census estimated 65,000 unpaid carers in Leeds. People providing unpaid carer can receive support through their GP in the form of vaccinations, or they can approach the Local Authority / Adult Social Care (LA / ASC) to access services such as home care, sitting services and direct payments through a carers assessment. Between 1/1/2016 and 31/12/2021 there were 1,977 referrals for a carer assessment from a maximum of 1,361 known individuals and 20,919 people who registered as a carer through their GP.

Analysis presented here shows;

1. 3.4% of the Total Leeds population registered as a carer through their GP compared to 0.2% seeking support through Adult Social Care
2. The ratio of female to male carers is greatest (approximately 2:1) in those seeking ASC support and substantially greater for all carers than the Leeds population (approximately 1:1).
3. On average, 225 carer assessments take place each year and typically those seeking ASC support are more likely to be female and older, compared to those who approach their GP.
4. 38% of those carers who have a carer assessment receive a support plan to provide services.
5. It is impossible to determine the total number of carers seeking Local Authority support from the data available. Only carers referred for a carer assessment were included here.

It should be noted that the interpretation of analysis features was limited by small numbers of carers, especially with Local Authority data and cannot be considered representative of the carer population in Leeds.

Key analysis:

There was a wide representation of unpaid carers aged 18 to 102 from across Leeds. Females, between the age of 50-59, living in the most deprived areas (IMD decile 1) typically had the most carers assessments and were most likely to register with their GP

Gender: Between 2016 and 2021 Leeds had an average of 320,896 (51.5%) females and 301,769 (48.5%) males over 18 (f/m ratio of 1.06). In contrast, the average ratio was 1.82 and 2.23 for GP registered carers and carers seeking council support respectively.

Age-Band: GP registered carers tend to be younger, whereas the LA cohort has a greater proportion of older carers. In both cohorts, younger carers are underrepresented and older carers overrepresented compared to underlying population in Leeds.

Inequities in service provision: Between 2016 and 2021, 533 (39.5%) of 1,350 carers who were referred for a carers assessment received support. The criterion for carer support is independent of age, gender, financial status and other demographic information and this is consistent with the analysis conducted here. However, considering such small numbers of overall referrals, it is surprising that approximately 60% of unpaid carers do not meet the criteria for support.

Ultimately, only 0.82% of the estimated carers, or 0.086% of the population over 18 in Leeds receive carer support through a carer assessment.

Analysis

A total of 22,280 unpaid carers were identified through GP records and Local Authority (LA) data. However, there were significantly less carers identified in both GP and LA cohorts, than expected from 2021 census estimates. Between 2016 and 2021, there were a total 20,919 carers over the age of 18 registered with their GP (3.4% of Total Leeds population or 32% of expected carers) compared to 1,361 (0.2% or 2.1%) referred for a carers assessment through their local authority.

Despite a substantial disparity in overall cohort sizes, it was possible to make direct comparison between the demographic characteristics of GP registered carers, those referred for a carers assessment, and the underlying population of Leeds.

Unfortunately, demographic characteristics (age, gender, postcode / IMD) were partially recorded for many carers which further reduced the cohort sizes for analysis. There were 2,547 (12.2%) GP registered carers whose age and gender were unknown, and 7,551 (36%) who couldn't be associated with their IMD. Similarly, of carers referred for an assessment, 290 (21%) did not have their age recorded and 50 (3.7%) could not be identified with an IMD.

Each cohort was broken down by gender, age-band and IMD decile and the proportional make-up (expressed as a %) could be compared across cohorts (GP vs LA vs Total Leeds population).

Study period and Inclusion criteria:

Records between 1/1/2016 and 31/12/2021 were extracted from GP and LA data. Any events before or after these dates were discarded. Carers identified by their GP or referred for a carer assessment between these dates were included in the analysis. GP Carers under the age of 18 who did not have demographic information recorded were removed from the dataset. Carer assessment referrals made between 1/1/2016 and 31/12/2021 where the carer was identifiable and 18+ at the date of referral were included. Referrals where the carers age was unknown were also retained to maximise the cohort size. 1,350 individual carers and 1,477 referrals were included in analysis of Local Authority support.

It was difficult to identify the total number of people attempting to access carer services through Adult Social Care. If they were not deemed eligible for referral, people received information and signposting, but it was not clear what for, so it was not possible to identify them as an unpaid carer.

The analysis describes demographic characteristics of the study population. There is potential for further analysis on ethnicity, regional distributions, health risk factors, and long-term conditions through linkage to wider LDM assets and calculation of Cambridge Multimorbidity Index (CMI). Though the data set is small limiting disaggregation of data by these characteristics. Key statistics from breakdowns by age band, gender and IMD decile are stated in the text and included in supplementary tables (TX-X). Figures show values after removing carers with missing characteristics.

It is likely that a small number of carers are represented in both the GP and LA data, however they could not be directly identified due to difficulties associating LA records with their NHS pseudo-identifier.

Demographic Characteristics of Unpaid Carers

There was a wide representation of unpaid carers aged 18 to 102 from across Leeds. Carers were most likely Female, between the age of 50-59, living in the most deprived areas (IMD decile 1). Typically, they had the most carers assessments and were most likely to be registered with their GP.

Gender

Leeds has 320,896 (51.5%) females and 301,796 (48.5%) males. On average, 67.3% percent of carers known to LA are female, compared to 30.7% male (with 2% unspecified gender) whereas 56.4% and 31.4% of GP registered carers are female and male respectively (12.2% are unknown) (T1-3).

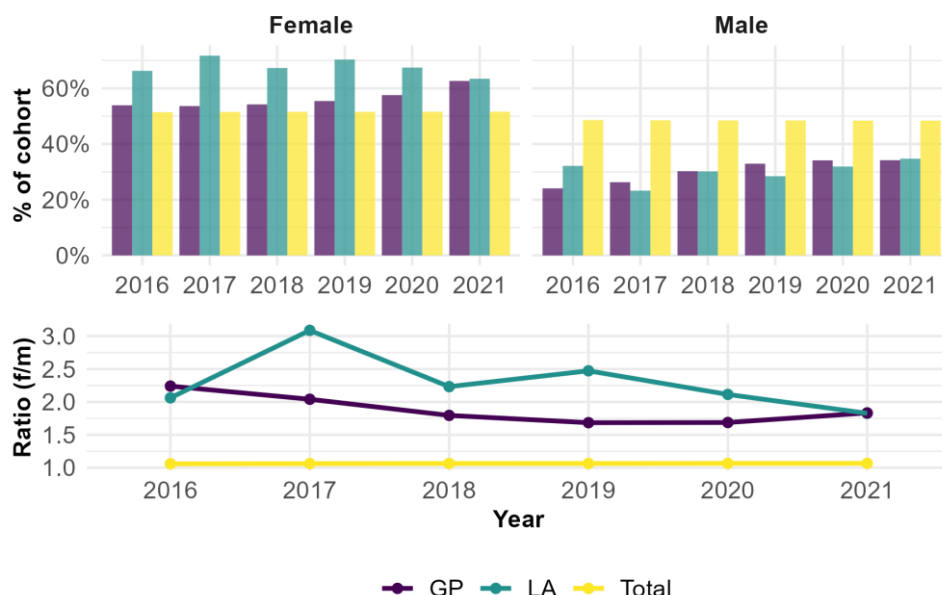


Figure 1: Percentage of Female (upper left) and Male carers (upper right) in GP and LA cohorts between 2016 and 2021, compared to the percentage of Males and Females in the Total population of Leeds. The ratio of females to males for each cohort between 2016 and 2021 (lower).

Between 2016 and 2021 the percentage of female carers in both cohorts was consistently greater than the Leeds population, whilst the percentage of male carers was consistently less. Figure 1 (upper left) shows that the percentage of female carers registering with their GP steadily increased from 53.9% in 2016 to 62.6% in 2021. Figure 1 (lower) shows the ratio of females to males is consistently higher than the general population and more pronounced for carers known to the Local Authority with a ratio greater than 2:1 in every year apart from 2021 (there were legacy data issues in 2016).

Age-Band

The largest proportion of carers were between 50-59 years old with 3,899 (18.6%) and 248 (18.2%) for GP and LA cohorts respectively, followed by the 70-79 age band with 2,893 (13.8%) and 227 (16.7%), including carers who don't have their age recorded. There were only 22 (1.62%) carers between 18-29 years old referred for a carer assessment and 1,318 (6.3%) registered through their GP (T1-2).

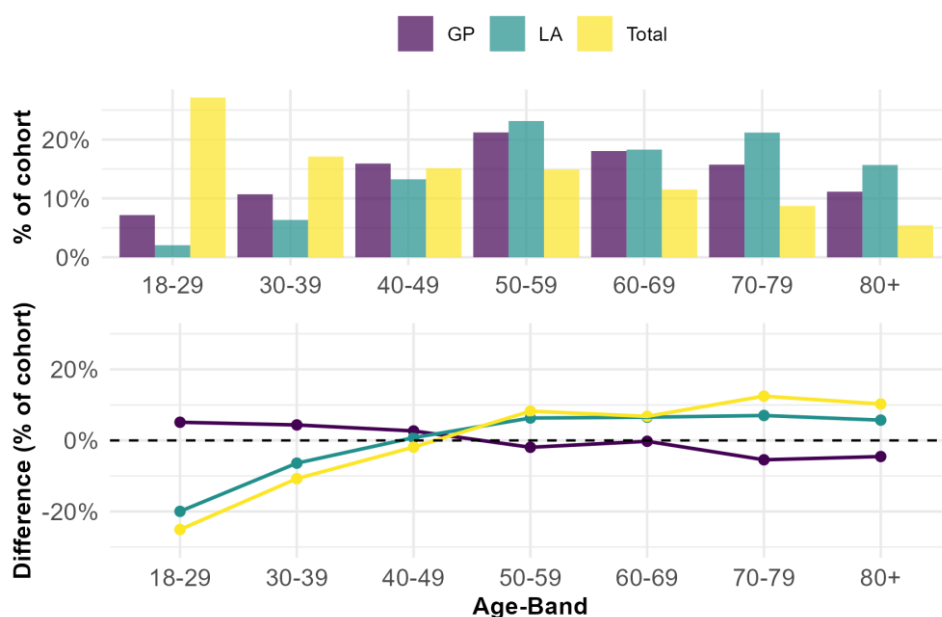


Figure 2: Percentage of carers in each age-band for GP and LA cohorts compared to the Total population of Leeds (upper). The difference in percentage between GP and LA cohort (purple) and the difference between GP and LA cohorts and Total Leeds population (green and yellow respectively).

Figure 2 (lower) shows how each cohort differs to the underlying population and how the GP and LA cohorts differ from each other. The purple line shows that the GP cohort has a greater proportion of younger carers, whereas the LA cohort has a greater proportion of older carers. Furthermore, the LA cohort has a far smaller proportion of younger carers, and the GP has a far larger proportion of older carers than would be expected from the underlying population.

IMD Decile

2,674 (12.8%) of GP registered carers and 286 (21.0%) of carers known to LA were from the most deprived areas of Leeds, almost double IMD decile 7, the next largest group of 1,668 (7.97%) and 159 carers (11.7%). IMD decile 4 and had the lowest number of carers with 528 (2.52%) and 64 (4.7%) respectively (T1-4).

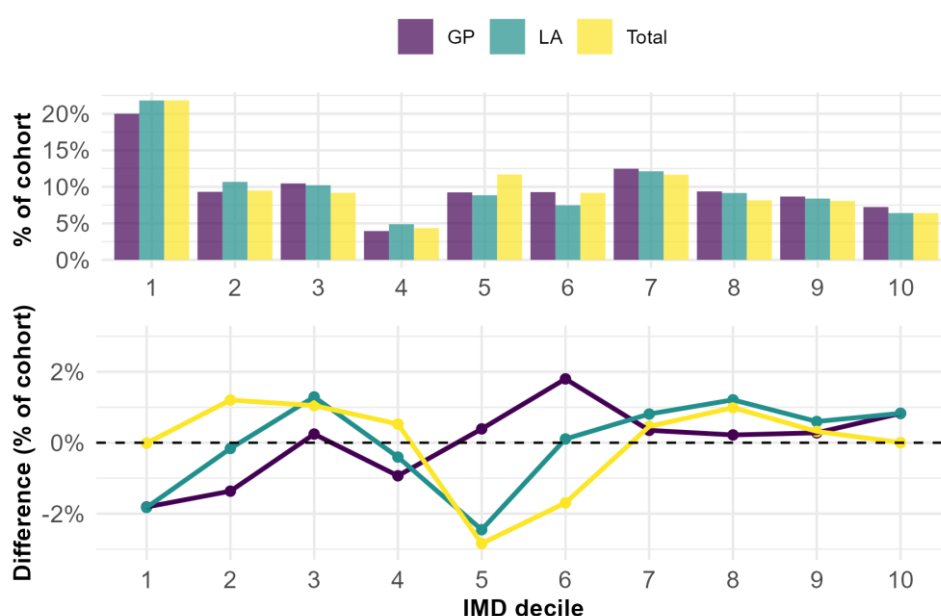


Figure 3: Percentage of carers in each IMD decile for GP and LA cohorts compared to the Total population of Leeds (upper). The difference in percentage points between GP and LA cohort (purple) and the difference between GP and LA cohorts and Total Leeds population (green and yellow respectively).

Unfortunately, the large numbers of carers who could not be assigned IMD according to their postcode meant it was difficult to establish any differences with certainty. Figure 3 (lower) shows that both GP (purple) and LA (yellow) cohorts were within +/-3% of the Total population and could be considered consistent with the underlying population. The largest deviation was an under-representation of carers in IMD decile 5. Again, the percentage of each deprivation category was similar between GP and LA cohorts with some evidence that carers from areas of lower deprivation were more commonly known to Local Authority.

Carer Identification between 2016 and 2021

Using a one year look back period it was possible to assess how GP and LA cohorts changed over the study period.

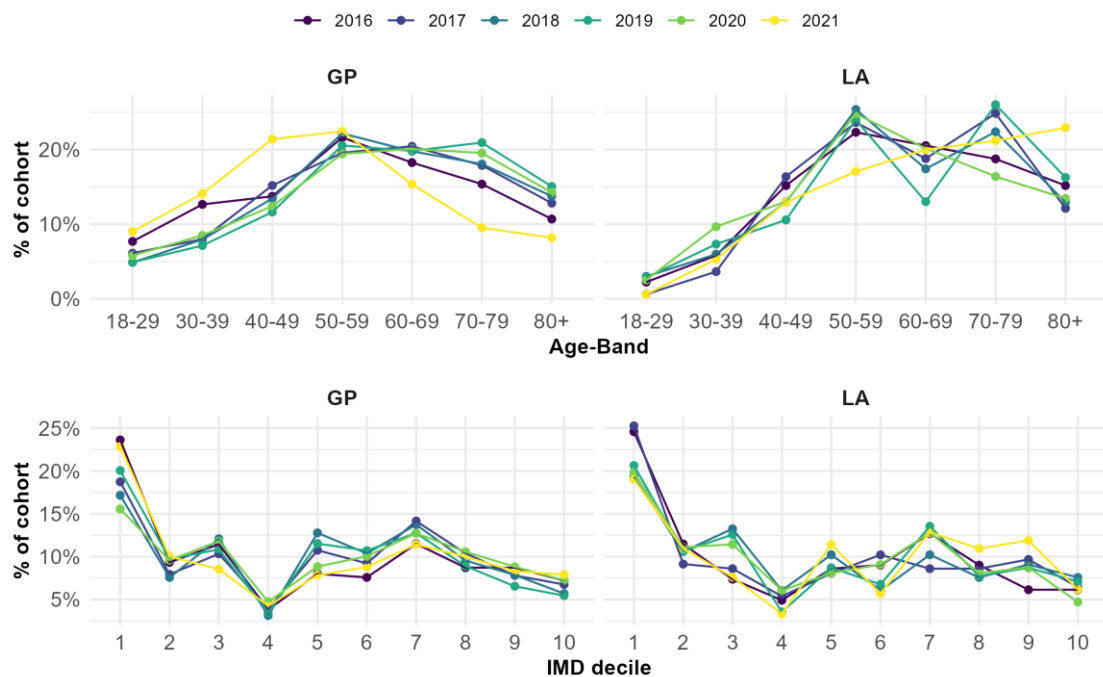


Figure 4: Comparison of yearly percentage of carers in each age-band for GP (upper left) and LA cohort (upper right). Percentage of carers in each IMD decile between 2016 and 2021 for GP (lower left) and LA cohort (lower right).

The ratio of females to males between 2016 and 2021 has been described for each cohort and relative to the local population in section above. Figure 4 shows that the LA authority cohort has a greater representation of 50-59 and 70-79-year-olds than GP registered carers (upper). Trends in IMD are representative of the underlying population and appear consistent over time (lower). However, data from 2021 shows the most noticeable difference in the age profile between cohorts. In 2021, the GP cohort showed an increase in percentage of younger carers (40-49) and a decrease in older carers (80+). Conversely, the LA cohort showed a relative reduction in carers between 50-59 and an increase of 80+ year-olds.

Carer Assessment Support

Social services assess carer needs according to several issues which may be affecting them such as their feelings about being carer, getting enough sleep, impact on their health, finances, personal relationships and whether the person they care for is receiving the care they need. Between 2016 and 2021, 533 (39.5%) of 1,350 carers who were referred for a carers assessment received support.

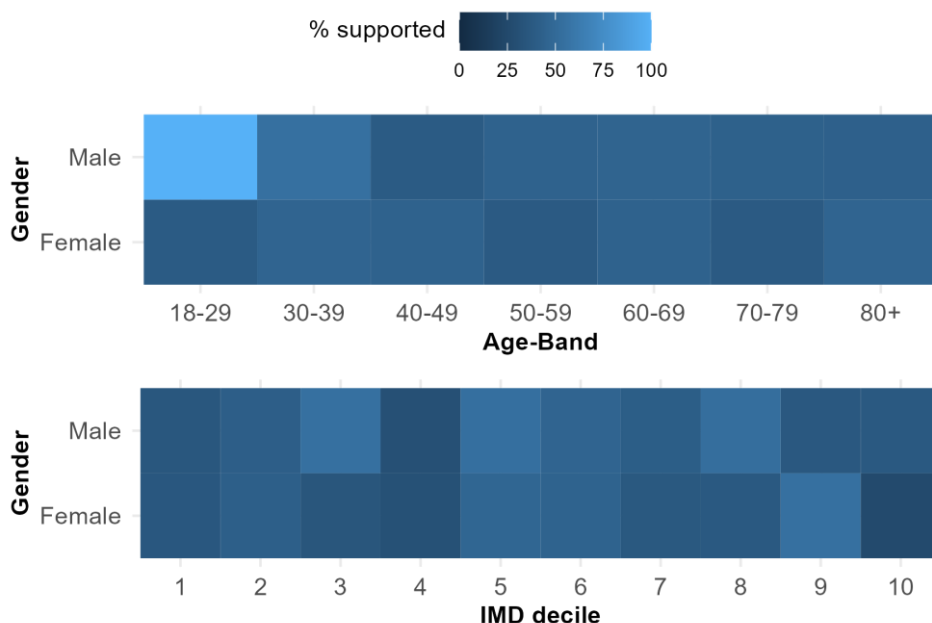


Figure 5: Percentage of carers who received a support plan as a result of seeking support broken down by gender and age band (upper) and gender and IMD decile (lower).

Figure 3 shows that the percentage of carers who receive a support plan does not vary significantly across age band, gender (upper) and IMD (lower), except for Males between 18-29 years old. The profile of those receiving support does not reflect the underlying population of Leeds. The criterion for carer support is independent of age, gender, financial status and other demographic information and this is consistent with the analysis conducted here. It should be noted that this observation requires further investigation and maybe an artefact of a small cohort and highly variable pathway from carers assessment to support.

Conclusions and Discussion

The 2021 national census registered approximately 65,000 carers in Leeds, yet only 32% (3.4% of the total population 18+) and 2.1% (0.22%) are known to GP and the Local Authority (LA) / Adult Social Care (ASC) respectively. The number of registered carers is evidently lower than estimated in 2021 census, and further investigation is needed to establish why.

This analysis attempts to compare demographic characteristics between GP registered carers, those referred for a carer assessment, and how they compare with the underlying population of Leeds. Leeds has 320,896 (51.5%) females and 301,796 (48.5%) males, however the ratio of female to male carers is consistently greater in GP and LA cohorts from 2016 and 2021. It is unclear why the proportion of females to males is different to the underlying population. The proportion of females to males is most pronounced in carers seeking council support in early retirement (50-59 years old) and it maybe that females have a heavier cultural burden to provide care for family members, or possibly a greater willingness to identify as carers. In contrast, deprivation characteristics of carer cohorts were consistent with the underlying population. It should also be noted that the female / male ratio was greater for carers seeking council support, and they also tended to be older than those registering with their GP.

The characteristics of both cohorts remained consistent over time, except for 2021, where carers identified through their GP shifted to younger age bands, in contrast to more older people seeking support through LA. This could be due to COVID-19 impacting access to support, or the different benefits offered by GP practices compared to Local Authorities.

From the data available, it was not possible to determine the total number of carers who approached Leeds City Council seeking support, were deemed ineligible, and/or were sign-posted to Carers Leeds. On average, 225 carer assessments take place each year and, overall, 38% of those carers who have a carer assessment receive a support plan to provide services, and this appears independent of gender, age and deprivation. The pathway from referral to service provision cannot be easily determined because there are often several conversations before a support plan is made.

It is difficult to say whether the analysis presented here is a fair reflection of support provided to unpaid carers in Leeds, and it emphasises the need for thorough evaluation of data sources to inform study design and better understanding of carer activities in Leeds.

Acknowledgements

Information on support to unpaid carers in Leeds is not readily available and the lived experience of unpaid carers has been invaluable throughout this analysis. Contributions from the Task and Finish (TF) group provided timely insight and context to the data. Leeds City Council helped identify carers and report from the case management system. Fruitful conversations with colleagues in Adult Social Care made processes around carer assessments and provision of support much easier to understand. The Health Foundation is acknowledged for their expertise, funding and clear study design.

Appendix

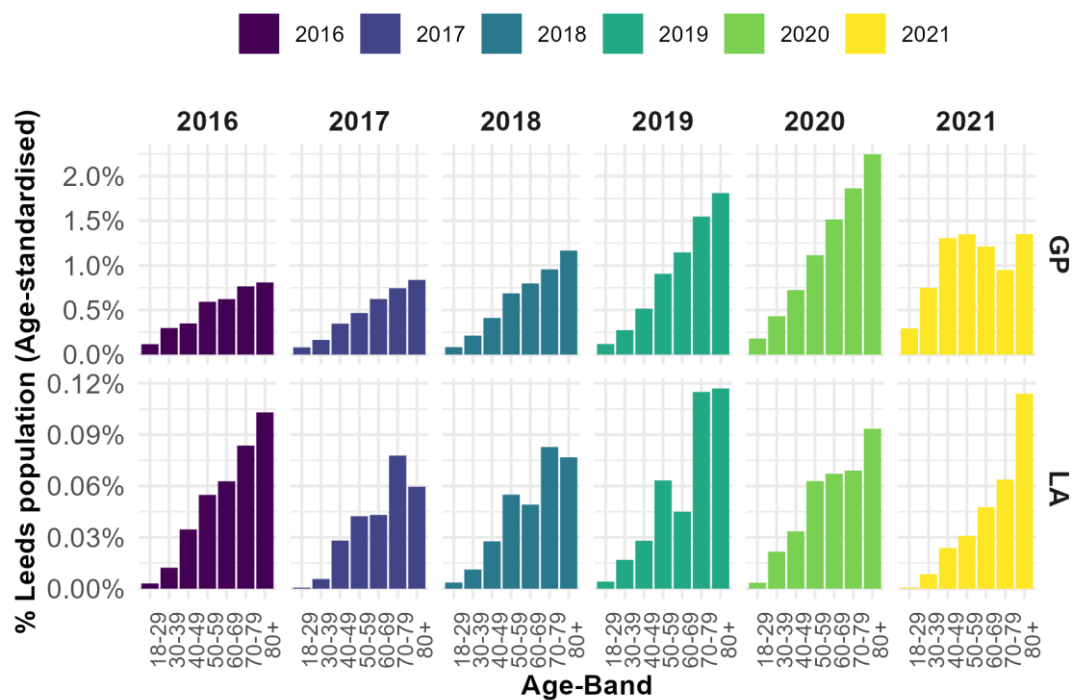


Figure A1: Age standardised comparison of carer inclusion between GP and LA cohorts from 2016 to 2021

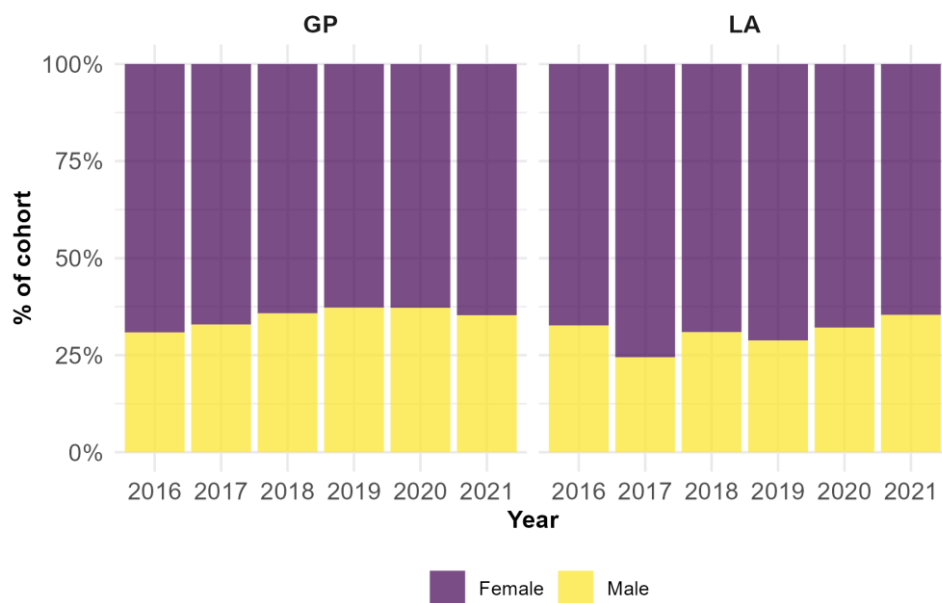


Figure A2: Yearly change in percentage of females and males for GP registered carers (left) and carers referred for a carers assessment.