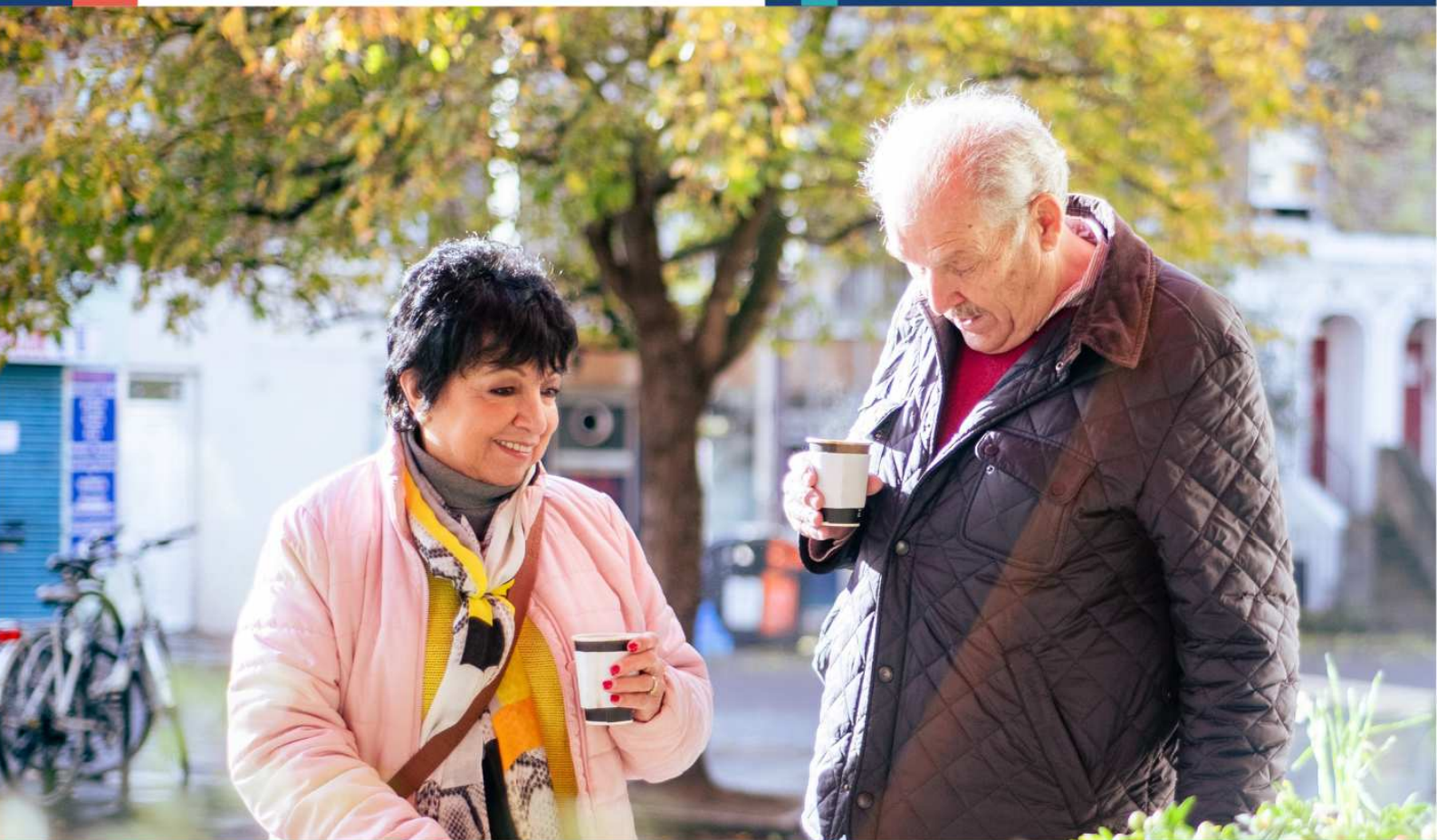




# Dementia Care After Diagnosis: What National Data Tell Us About Patterns, Demand and Inequalities in Health Service Use

## Interim report

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## Dementia Care After Diagnosis: What National Data Tell Us About Patterns, Demand and Inequalities in Health Service Use

### Authors



**Professor Matthew Prina**  
Leadership Team



**Dr Laura Gamble**  
Research Fellow (until October 2025)



**Emily Adams**  
Impact and Engagement  
Manager (until Feb 2026)



**Professor Karen Windle**  
Leadership team



**Professor Dame Louise Robinson**  
Leadership team



**Dr Michael Pan**  
Research Fellow



**Dr Magdalena Walbaum**  
Research Fellow



**Dr Yu-Tzu Wu**  
Lecturer



**Dr Catherine Quinn**  
Leadership Team



**Professor Linda Clare**  
Leadership team



**Adelina Comas Herrera**  
Leadership Team



**Professor Martin Knapp**  
Leadership Team

**Rick Nelms**  
Lived Experience

Correspondence to: [denpru@exeter.ac.uk](mailto:denpru@exeter.ac.uk)

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## Summary

Dementia is a major and growing driver of health and social care demand in England. Yet the system currently lacks a unified, evidence-based understanding of how people with dementia use primary and secondary care in the year following diagnosis, how patterns vary across population groups, and which inequalities remain after accounting for clinical need. Integrated Care Systems (ICSs) are expected to deliver the shift from hospital-led to community-led dementia care, but they cannot do so effectively without a clear view of current utilisation, costs, and unwarranted variation.

This interim report provides that foundation. It presents early quantitative findings from a large national cohort analysis of 33,063 people diagnosed with dementia between April 2021 and March 2022, linked across primary care (CPRD) and secondary care (HES) datasets. The results describe how people with dementia use GP, community and hospital services in the year after diagnosis, how patterns differ across demographic and geographic groups, and where persistent inequalities remain.

### Key findings

#### 1. Dementia generates a consistently higher level of activity across the health system.

People with dementia had almost double the primary care contacts of matched controls (median 13 vs 7), and substantially higher hospital use (49% admitted at least once within a year, compared with 32% of matched adults). Hospital use was not only more common, but more intensive: people with dementia had more admissions and far longer cumulative lengths of stay.

#### 2. Inequalities are visible across both primary and secondary care, but patterns differ by setting.

In primary care, the most pronounced inequalities were by ethnicity and region; in secondary care, by age, sex, deprivation, urban/rural setting, and region. These differences persisted even after adjusting for clinical need, indicating structural rather than solely clinical drivers.

#### 3. Deprivation is a strong and independent predictor of hospital burden.

People living in the most deprived areas had higher adjusted risks of hospitalisation, more frequent admissions, and longer stays. This pattern remained strong in both post-COVID and pre-COVID analyses.

#### 4. Ethnic inequalities in primary care remain after adjustment, but largely disappear in hospital care.

Asian and Black groups continued to have higher adjusted primary care contact rates, suggesting differences in care-seeking or service configuration. In contrast, ethnic differences in hospital volume diminished once comorbidity and prior use were accounted for, indicating that the higher crude rates reflect underlying health need rather than inequitable access.

#### 5. Regional variation is extensive and persistent.

People registered in the North East and North West consistently had lower primary care contact rates, even after adjustment, while London and the South West had higher use. In hospital care, London had significantly higher adjusted hospital use and the South West significantly lower, reflecting variation that may stem from service availability, local pathways, or system capacity.

## 6. Dementia care costs remain substantially higher than for matched adults.

Primary care costs were nearly double those for matched individuals, and hospital costs were more than twice as high. Costs were particularly elevated among older adults, men, people in deprived areas, and several minority ethnic groups. The wide interquartile range in hospital costs points to a small group of very high-cost hospital users, a pattern with major implications for resource planning.

### Key messages

- Dementia is a predictable, high-demand condition that requires planned, proactive community support to avoid crisis-driven hospital care.
- Primary care is absorbing substantial workload, but access and activity are uneven across regions and ethnic groups.
- Hospital use reflects socioeconomic gradients, with the most deprived communities experiencing the greatest inpatient burden.
- Regional variation is wide, suggesting different models of care and possible opportunities for learning between areas.
- Costs of dementia care are materially higher, driven by both high-volume primary care contact and high-cost hospital activity.
- The strongest inequalities, ethnicity in primary care, deprivation and region in hospital care, are not explained by clinical need, indicating system-level rather than patient-level causes.



## Background

Dementia represents one of the most significant structural challenges to the sustainability of the UK health and social care system. Current estimates indicate that over 900,000 people are living with the condition, a figure projected to exceed 1.2 million by 2040 (1). The economic impact is profound, with annual costs estimated at £42 billion (2). Crucially, the current model of care is often reactive, characterised by high costs in the acute sector and heavy reliance on the informal care provided by families.

The NHS 10 Year Health Plan (3) sets out a mandate for fundamental reform through three strategic shifts: moving from analogue to digital, from sickness to prevention, and, most critically for this cohort, is mobilising care from hospital to community. To deliver the proposed 'Neighbourhood Health Service', Integrated Care Systems (ICSs) must reduce reliance on acute settings and proactively manage complex long-term conditions closer to home. However, as highlighted by the recent Lord Darzi investigation (4), fragmented pathways currently result in high rates of avoidable emergency admissions and "unwarranted variation" in care quality and accessibility, and the current system is not yet configured to deliver this shift. Without a clearer understanding of how people with dementia use primary care, community services, and hospitals, it is difficult for ICSs to redesign pathways or allocate resources effectively.

A core ambition of current reform efforts is to strengthen the foundation of primary and community care so that people receive the right support earlier and in the most appropriate setting. However, achieving this objective requires a clear understanding of how people with dementia currently use services, how patterns of care differ between population groups, and whether the distribution of primary care aligns with levels of need. Existing UK-specific evidence is limited (5), particularly in quantifying interactions across the whole system and in assessing inequalities by age, deprivation, ethnicity, and geography.

This report addresses that gap by analysing linked national datasets to provide an up-to-date picture of primary and secondary care use in the year following a dementia diagnosis. By examining both activity and associated costs, and by exploring variation across different demographic and geographic groups, the analysis offers essential insights for DHSC and ICSs as they work to design and implement a more equitable and sustainable community-centred model of dementia care.



## What we did

We conducted a multi-method study combining: a) quantitative analyses of primary and secondary care utilisation; b) public and patient involvement and engagement (PPIE) through stakeholder consultations; c) a review of reviews to assess the impact of inequalities in dementia healthcare utilisation. For this interim report, we will only present results from the quantitative analyses.

### Statistical analyses

We used a multi-method approach to provide a contemporary picture of how people with dementia use primary and secondary care services in England. The analysis was based on a national cohort of **33,063 people diagnosed between April 2021 and March 2022**, each followed for twelve months to understand patterns of care during the first year after diagnosis. To explore whether the observed patterns differed before and after the COVID-19 pandemic, we conducted parallel analyses using the 2018-2019 data and compared the resulting estimates with those from the post-pandemic period.

To do this, we used linked electronic health records from two national datasets. The Clinical Practice Research Datalink (CPRD) (6) provided detailed information on primary and community care activity, including consultations, prescribing, tests and referrals. Hospital use, including admissions, length of stay and inpatient costs, was captured through linkage with Hospital Episode Statistics (HES) (7). Using both datasets together allowed us to track activity across the whole system and understand how people move between community and hospital settings.

The analysis proceeded in several stages.

1) We described the demographic and clinical characteristics of the cohort using standard descriptive statistics. We summarised service use, such as numbers of GP contacts, hospital admissions, and days spent in hospital, and compared these with matched control groups drawn from the same datasets. Controls were matched on year of birth, sex, and region to allow a meaningful comparison between people with dementia and those without the condition; they are described as the 'matched sample'.

2) To understand patterns of planned and unplanned hospitalisation, we examined the risk of patients being admitted to hospital within a year of diagnosis. Because a proportion of people died before any hospital admission occurred, we used a competing risk approach that allows hospitalisation risk to be estimated while accounting for death as an alternative outcome. This modelling allowed us to examine whether the observed differences in hospitalisation risk across demographic and geographic groups persisted once we accounted for underlying health needs, including comorbidities, and individuals' previous patterns of hospital use

3) We assessed hospital resource intensity by identifying those who fell within the top ten percent for the number of admissions, total days spent in hospital, and the overall costs of hospital care. Logistic regression models were then used to explore which groups were most likely to become high resource users.

4) To estimate the financial implications of service use, we applied nationally recognised costing frameworks to all primary and secondary care activity recorded during the 12-month follow-up period. Primary and community care costs were calculated using the 2022/23 PSSRU Unit Costs of Health and Social Care, which provide standardised valuations for GP consultations, practice nurse contacts, administrative activity and other community-based services recorded in CPRD. Hospital costs were derived using the NHS HRG4+ 2022/23 National Costs Grouper, which assigns each HES Admitted Patient Care episode to a Healthcare Resource Group (HRG) and links it to the corresponding national reference cost. Together, these sources allowed us to produce consistent, comparable estimates of the costs associated with primary care contacts, hospital admissions, inpatient bed days and overall secondary care use across patient groups

Across all analyses, we examined whether patterns differed by characteristics, allowing us to identify groups that may be underserved or disproportionately reliant on hospital care. We included:

- **Age group.** We classified patients by age groups, namely: 80 years and older, 75-80 years, 70-74 years, 65-69 years, and below 65 years.
- **Sex.** Patients were grouped into binary sex categories, namely male and female, respectively.
- **Ethnicity.** To determine patients' ethnic groups, we used the information from the Hospital Episode Statistics (HES) Admitted Patient Care (APC) and medical codes associated for each patient. Ethnicity was categorised as White, Black, Asian, Mixed, or Other.
- **Deprivation.** We used the Index of Multiple Deprivation (IMD) quintiles to create categories of the deprivation levels of where people live, where the First Quintile refers to areas that are least deprived while the Fifth Quintile are areas that are considered most deprived.
- **Geography.** This refers to the location of the GP practice where the patient is registered for primary care services, namely urban vs. rural locations, respectively. We also included an indicator to identify which region the GP practice is located in.

## What we found

### 1. Descriptive utilisation patterns

A total of 33,063 people received a new dementia diagnosis between April 2021 and March 2022 and were followed for twelve months. Due to differences in data availability across settings, the number included in the primary and secondary care analyses varied. For primary and community care activity, 20,906 people with dementia met the full inclusion criteria. For hospital analyses, including admission patterns and secondary care costs, 26,544 people had successfully linked HES data.

#### 1.1 Primary and community care utilisation

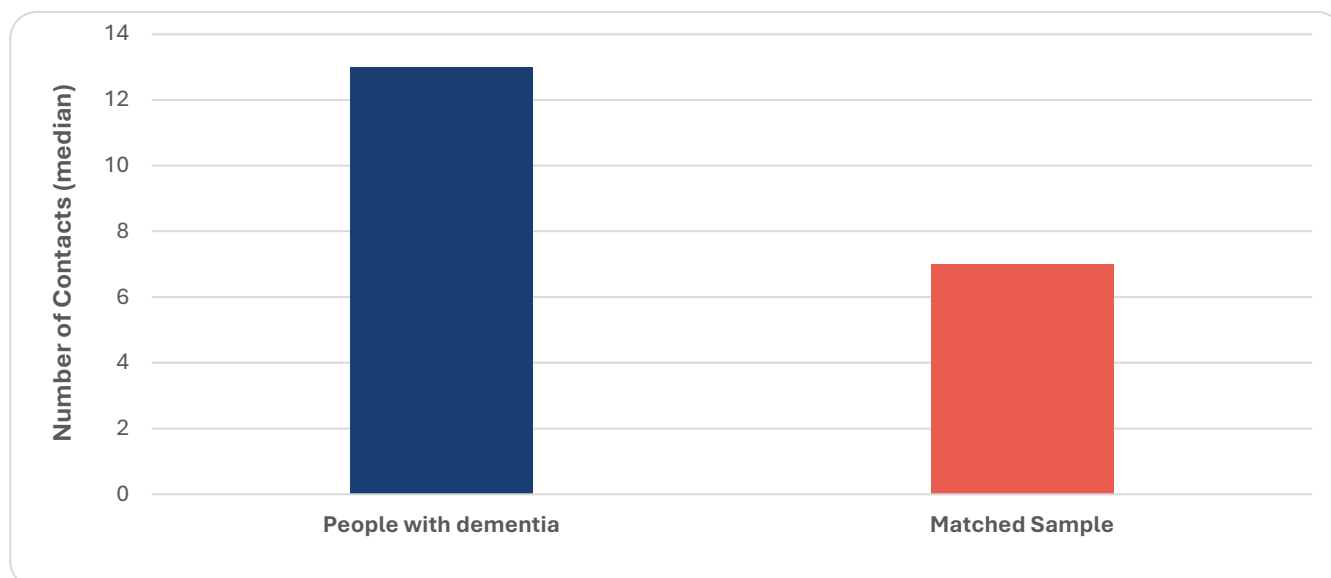
People with dementia had substantially higher levels of primary and community care activity in the year after diagnosis than the matched sample (matched on age, sex and region). Only 2% (420 people) had no recorded primary care contact in the first-year post-diagnosis. The median number of contacts was 13 (IQR 13), nearly double the 7 contacts (IQR 10) in the matched cohort. The mean number of contacts also showed a clear gap (14.9 vs 9.6), reinforcing that dementia places a consistently higher and ongoing workload on primary care teams (**Table 1; Figure 1**).

**Table 1. Number of contacts 12 months after a diagnosis compared to matched sample**

|                              | Living with Dementia | Not living with dementia |
|------------------------------|----------------------|--------------------------|
| <b>Median contacts (IQR)</b> | 13.0 (13. 0)         | 7.0 (10.0)               |
| <b>Mean contacts (SD)</b>    | 14.9 (10.8)          | 9.6 (9.1)                |

*IQR – interquartile range (the spread of the middle 50% of the dataset). SD – standard deviation (the spread of data points relative to the mean).*

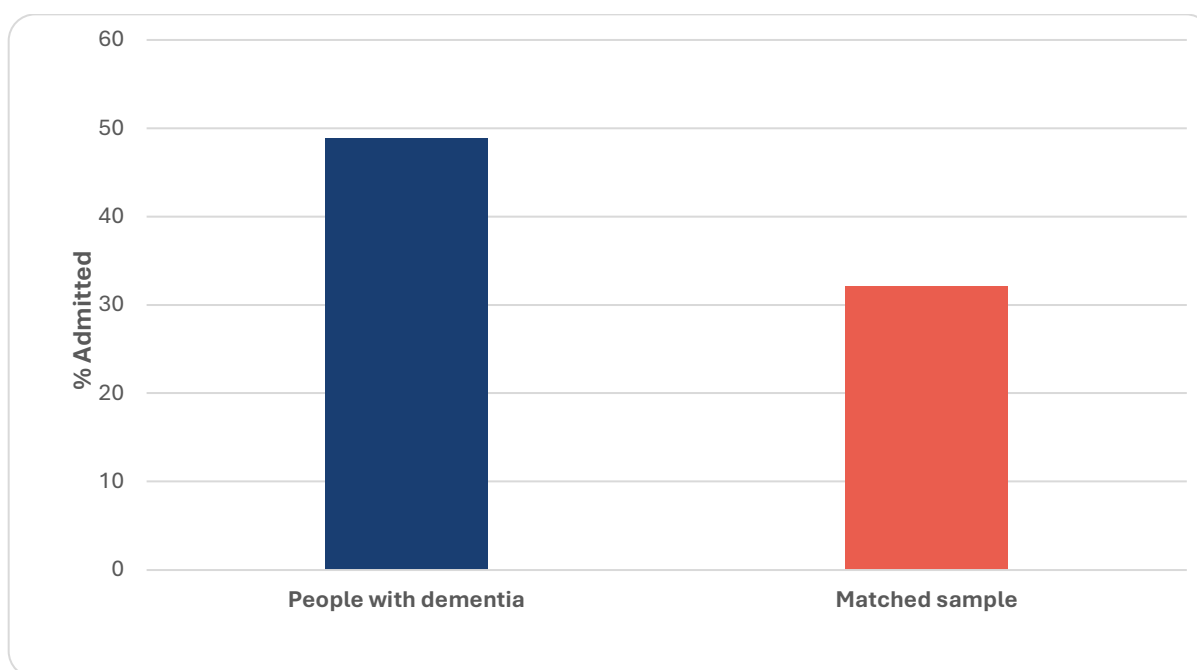
**Figure 1. Median number of primary care contacts 12 months post-diagnosis compared to matched sample**



## 1.2 Hospital utilisation

Patterns of hospital use were similarly elevated. Almost half of people with dementia (48.9%) were admitted to hospital at least once within 12 months of diagnosis, compared with 32.1% of the matched group (Figure 2). The mean number of admissions (1.1 vs 0.6) again highlights the greater reliance on unplanned and planned secondary care among people living with dementia

**Figure 2. Proportion of people admitted to hospital within 12 months of a dementia diagnosis compared to matched sample**



## 2. Inequalities in primary and community care

### 2.1 Descriptive analyses

Descriptive analyses indicated clear variation in primary care use across demographic and geographic groups (**Table 2; Appendix 1**), and these patterns were broadly mirrored among those not living with dementia. Ethnicity showed some of the most pronounced differences: people from Asian and Black ethnic groups recorded substantially higher levels of contact (medians 16 and 15 respectively) than White groups (median 12).

Geographic and regional differences were also visible. Contact levels were slightly higher for those registered with rural practices, and regionally were lower in the North East and North West and higher in London and the South West. These trends were largely consistent in the matched sample, indicating broader system-wide inequalities rather than dementia-specific effects.

**Table 2. Key descriptive inequalities in primary care use**

| Dimension      | Descriptive pattern for dementia                      | Pattern in matched sample |
|----------------|-------------------------------------------------------|---------------------------|
| Age            | Little variation (12–13 contacts)                     | Same direction            |
| Sex            | Minimal difference (means slightly higher for women)  | Same direction            |
| Deprivation    | Slightly lower in most deprived                       | Same direction            |
| Ethnicity      | Asian & Black groups higher                           | Same direction            |
| Urban vs rural | Rural slightly higher                                 | Same direction            |
| Region         | North East/North West lower; London/South West higher | Same direction            |

## 2.2 Adjusted inequalities after accounting for multimorbidity and prior hospital use

After full adjustment (Table 3), several inequalities in primary and community care use remained:

- Ethnicity showed the strongest independent differences. People of Asian ethnicity continued to have higher contact rates than White groups (Incidence rate ratio (IRR) 1.17), with similarly elevated rates for those of Black ethnicity (IRR 1.12). These effects persisted beyond differences in multimorbidity or prior service use.
- Geographic and regional inequalities also remained. Contact rates were slightly higher in rural practices, although this attenuated after accounting for baseline contacts. Regionally, lower adjusted rates persisted in the North East and North West, while higher use remained in the South West and London.
- Deprivation effects were weak and inconsistent. Adjusted analyses suggested only a slight increase in contact rates in the most deprived areas, indicating no clear deprivation gradient in post-diagnosis primary care use.
- Differences by age and sex were minimal. Younger age groups and women had adjusted contact rates very close to the reference groups, with no evidence of systematic under- or over-provision.

Pre-COVID findings showed similar patterns, though with a clearer deprivation gradient. This suggests that while deprivation-related differences may have narrowed post-COVID, ethnic and regional inequalities in primary care have been long-standing and persistent.

**Table 3. Comparison of adjusted inequalities in primary and community care contacts pre- and post-COVID**

| Inequality dimension   | Direction 2021–22    | Direction 2018–19   | Interpretation                |
|------------------------|----------------------|---------------------|-------------------------------|
| <b>Age</b>             | No differences       | No differences      | Stable                        |
| <b>Sex</b>             | No differences       | No differences      | Stable                        |
| <b>Asian ethnicity</b> | ↑ higher use         | ↑ higher use        | Stable, strong effect         |
| <b>Black ethnicity</b> | ↑ slightly higher    | ↑ slightly higher   | Stable                        |
| <b>Deprivation</b>     | Mixed/weak           | ↓ lower in deprived | Inequality stronger pre-COVID |
| <b>Urban/rural</b>     | Rural ↑              | Rural ↑             | Stable                        |
| <b>Region</b>          | NE/NW ↓; SW/London ↑ | NE/NW ↓; SW ↑       | Stable                        |

### 3. Inequalities in hospital use

#### 3.1 Descriptive analyses for hospitalisation

Descriptive analyses revealed clear and consistent inequalities in hospital use (**Table 4; Appendix 2**) not only in whether people were admitted, but in how often they were admitted, and the number of days they subsequently spent in hospital.

**Age** was a major factor, with people aged 80+ showing the highest number of admissions and the largest proportion in the “high resource” cohort (top 10% for admissions, bed days and costs). Younger adults (<65) had lower admission rates and far fewer high resource users.

**Sex** differences were also evident: men experienced more frequent admissions and were more likely to become high resource users (16.9% vs 14.8% for women).

Marked **ethnic** differences emerged in hospital volume. People of Black ethnicity had substantially higher mean admission counts (1.9) than those of White (1.1) or Asian (1.0) backgrounds, indicating greater frequency of hospital use once admitted.

A strong gradient by **deprivation** was visible, with those residing in the most deprived areas showing more admissions, greater likelihood of high resource use (18.0% vs 14.2%), and higher median and mean hospital use.

**Urban–rural and regional** variation were also substantial: hospital use was higher in urban areas, and highest in London and the North East

In conclusion, descriptive analyses showed clear and consistent inequalities in overall hospital use among people with dementia, with patterns that broadly mirrored those seen in the matched sample not living with dementia, though typically with larger absolute differences for the dementia cohort.

**Table 4. Summary of descriptive Inequalities in hospital use 12 months post-diagnosis**

| Dimension             | Hospitalisation                    | Number of hospitalisations                         | High hospital use (top 10%)                 |
|-----------------------|------------------------------------|----------------------------------------------------|---------------------------------------------|
| <b>Age</b>            | Higher in 80+                      | Higher in 80+                                      | Higher in 80+                               |
| <b>Sex</b>            | Higher in men                      | Higher in men                                      | Higher in men                               |
| <b>Deprivation</b>    | Higher with increasing deprivation | Higher in most deprived                            | Higher with increasing deprivation          |
| <b>Ethnicity</b>      | Slightly higher in Black and Mixed | Higher in Black, Mixed and "Other". Lower in Asian | Higher in mixed and "Other". Lower in Asian |
| <b>Urban vs rural</b> | Higher in urban                    | Higher in urban                                    | Higher in urban                             |
| <b>Region</b>         | Higher in London and North East    | Higher in London and North East                    | Higher in London                            |

### 3.2 Adjusted inequalities for hospitalisation after accounting for multimorbidity and prior hospital use

After full adjustment (**Table 5**), several inequalities remained strong:

- **Age** continued to be a dominant factor, with all younger age groups showing significantly lower risks of hospitalisation and lower volumes of hospital use compared with people aged 80+.
- **Women** consistently had lower adjusted risk and intensity of hospital use than men across outcomes.
- **Deprivation** effects remained strong, with materially higher risks of admission and higher inpatient burden in the most deprived communities.
- **Urban–rural differences** persisted, with lower use among rural populations even after controlling for need.
- **Regional inequalities** also remained: London retained higher adjusted hospital use, while the South West showed consistently lower levels across outcomes.

In contrast, **ethnic inequalities largely disappeared after adjustment**, implying that the higher observed volume among some ethnic groups reflects differences in underlying health status or prior hospital use rather than direct inequity in hospital access.

Pre-COVID results showed similar patterns but with a sharper deprivation gradient and slightly stronger ethnicity-related differences, suggesting that socioeconomic inequalities in hospital use remain persistent and were not created or amplified by the pandemic.

Table 5. Adjusted inequalities in hospitalisation

| Dimension                     | Risk of hospitalisation                              | Number of hospitalisations                           | High hospital use (top 10%)                          |
|-------------------------------|------------------------------------------------------|------------------------------------------------------|------------------------------------------------------|
| Age                           | Lower in all younger groups vs 80+ (strong gradient) | Lower in all younger groups vs 80+ (strong gradient) | Lower in all younger groups vs 80+ (strong gradient) |
| Sex                           | Lower in women than men                              | Lower in women                                       | Lower in women                                       |
| Deprivation                   | Higher risk with increasing deprivation              | Higher risk in most deprived (top two quintiles)     | Higher risk with increasing deprivation              |
| Ethnicity (reference White)   | No significant ethnic differences                    | No significant ethnic differences                    | Lower in Asian                                       |
| Urban vs rural                | Lower in rural                                       | Lower in rural                                       | No difference                                        |
| Region (reference South East) | Higher in London; Lower in the South West            | Higher in London; Lower in the South West            | Higher in London                                     |

#### 4. Dementia care costs post diagnosis

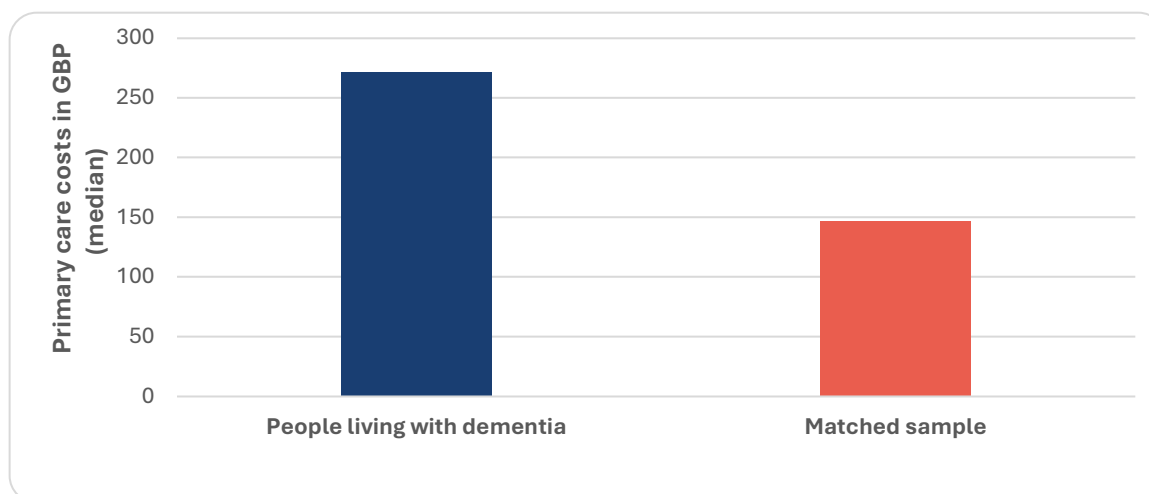
Across both primary and secondary care, people with dementia had substantially higher health care costs in the year after diagnosis compared with matched controls. Although primary and secondary care costs derive from slightly different underlying samples, the overall pattern is clear: costs were higher for people with dementia across every care setting examined.

Primary and community care costs were almost double in the dementia sample, with a median of £272 (IQR £296) compared with £147 (IQR £217) in controls. In secondary care, mean hospitalisation costs were more than twice as high for people with dementia (£3,058, SD £5,756) than for the matched sample (£1,387, SD £3,791). The median hospital cost was zero in both groups, but the interquartile range was almost four times larger for the dementia cohort (IQR £3,870 vs £978), reflecting a small proportion of very high-cost users.

##### 4.1 Primary care costs

Primary and community care costs in the year following a dementia diagnosis were substantially higher for people with dementia than for comparable individuals not living with dementia (**Appendix 3**). The median annual cost for people with dementia was £272, almost double the £147 recorded for the matched sample (**Figure 3**). This differential was consistent across every demographic and geographic group, suggesting that dementia has a systemwide impact on primary care workload, not confined to specific sub-populations or regions. From a policy perspective, this pattern indicates that dementia generates a predictable and sustained demand on primary care, with implications for workforce planning, funding allocations, and models of dementia capable general practice.

**Figure 3. Median primary and community care costs one year post-diagnosis compared to matched sample**



### Age

Primary care costs for people with dementia were broadly stable across all age groups, ranging from £247 in those aged under 65 to £280 in the over 80s. In the matched population, by contrast, costs were lower overall and showed a clearer age gradient (e.g., £89 in <65s vs £162 in 80+). This demonstrates that dementia, not age, is the primary driver of increased primary care activity. This highlights that the primary care resource requirement for dementia is relatively insensitive to age, meaning projections of population ageing should treat dementia demand separately from general age-related cost curves.

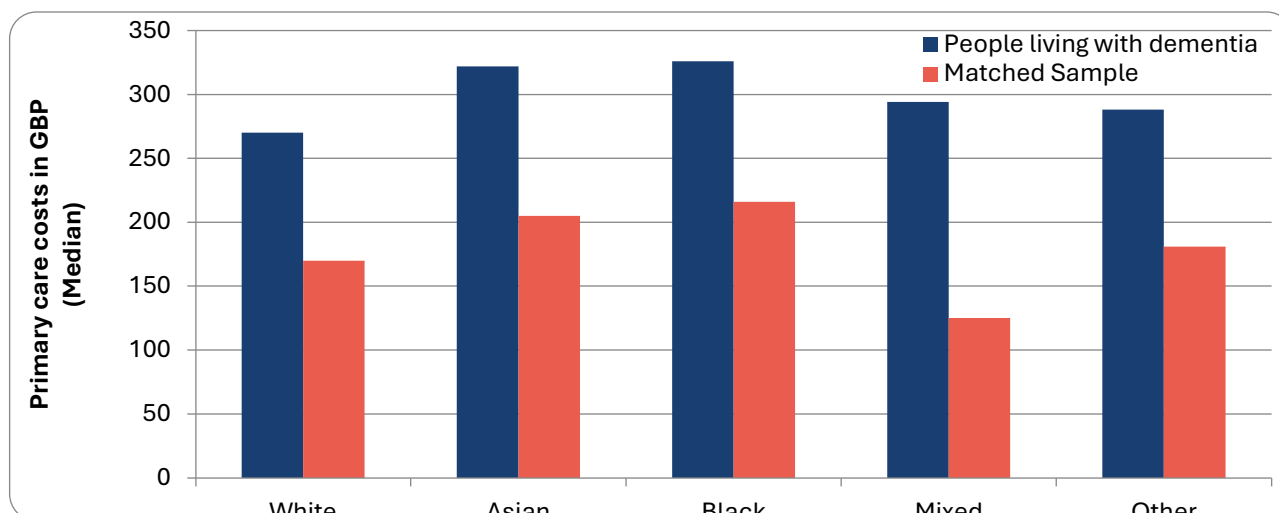
### Sex

Costs were very similar for men (£270, IQR £287) and women (£273, IQR £301) with dementia, reinforcing that dementia produces a uniform primary care burden across sexes.

### Ethnicity

Clear ethnic inequalities were evident, with Asian (£322) and Black (£326) groups incurring the highest median costs among people with dementia, compared with £270 among White groups. The same pattern—though at lower cost levels—was observed in the matched sample (**Figure 4**).

**Figure 4. Median primary and community care costs one year post-diagnosis stratified by ethnicity**



## Deprivation

Primary care costs for people with dementia were remarkably stable across deprivation levels, ranging from £270–£276 across IMD quintiles. By contrast, the matched population showed more pronounced variation.

## Urban-Rural context

Costs were similar in urban (£270) and rural (£290) areas for people with dementia, though the matched sample again showed lower values in both contexts

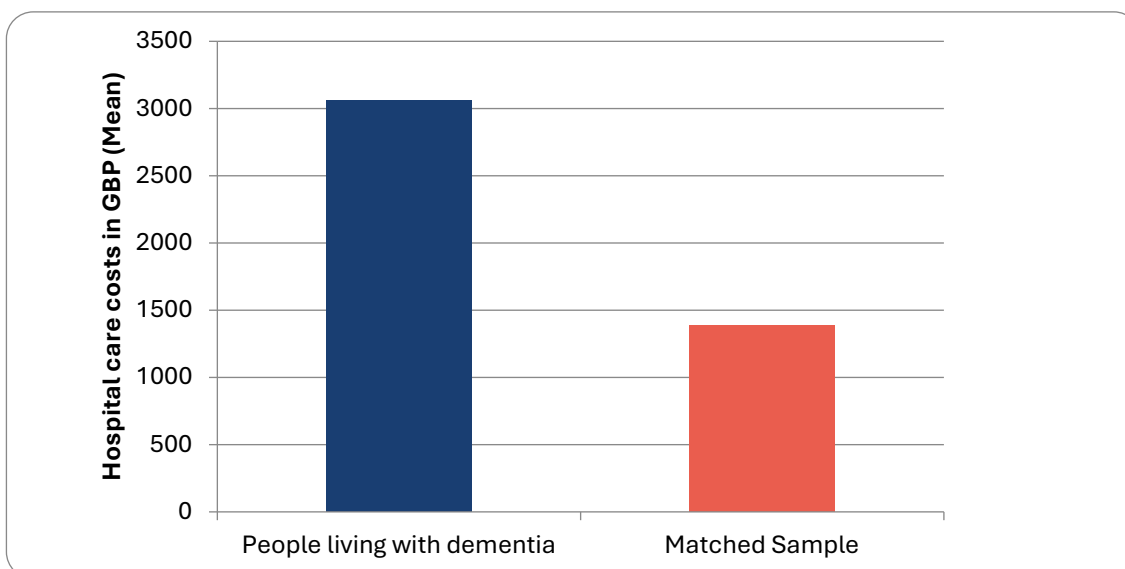
## Regional variation

There was substantial regional variation in primary care spending for people with dementia. London (£314) and South West (£291) had the highest median costs, while the North East (£231) and North West (£254) had the lowest.

### 4.1 Secondary care costs

Secondary care costs in the year following a dementia diagnosis were substantially higher for people with dementia than for the matched sample not living with dementia (**Appendix 4**). Mean hospitalisation costs for people with dementia were £3,058 (SD £5,756), more than twice the average for the matched group (£1,387, SD £3,791). Although the median hospital cost was £0 in both groups, reflecting that many individuals had no hospital admissions, the spread of costs was far wider for people with dementia (IQR £3,870 vs £978 in the matched sample), indicating a much higher concentration of high-cost users. This pattern highlights dementia as a major driver of intensive, and often costly, inpatient care, with implications for unplanned care pressures, delayed discharges, and downstream community care capacity.

**Figure 5. Median hospital care costs one year post-diagnosis compared to matched sample**



## Age

Hospitalisation costs within the dementia cohort showed a clear age gradient. Mean costs rose from £2,222 in those aged under 65 to £3,250 in those aged 80+. Median costs remained £0 across all ages, but the IQR widened substantially with age, indicating greater variability and a small group of very high-cost users among the oldest old.

## Sex

Men with dementia incurred higher mean hospital costs (£3,287) compared with women (£2,904) despite similar median values (women: £0; men: £302).

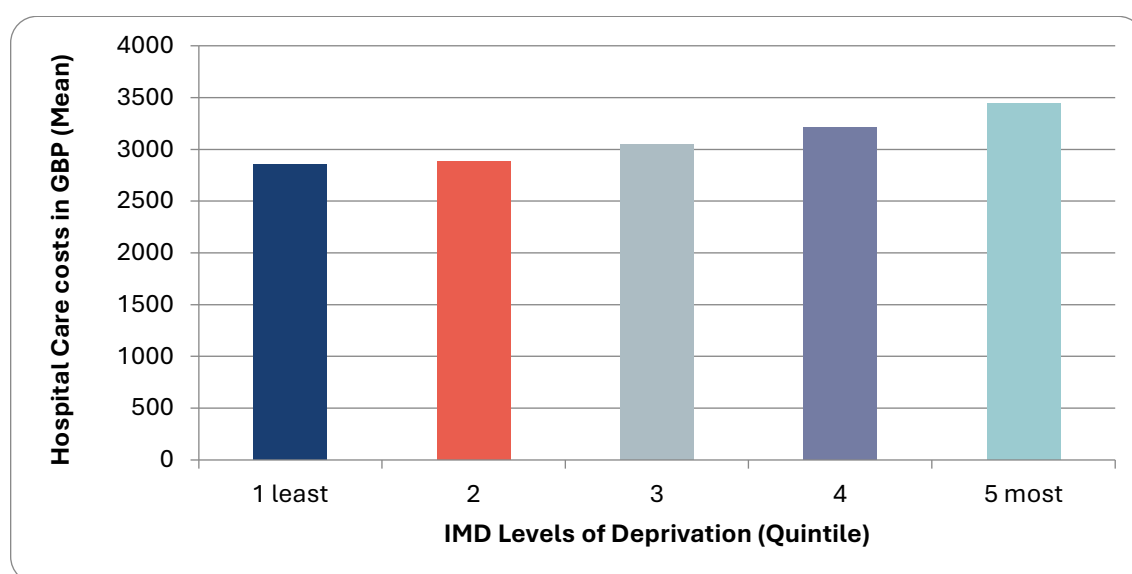
## Ethnicity

There were also differences between ethnic groups. Mean costs were £3,090 among White groups, £2,514 among Asian groups, £2,972 among Black groups, and higher still in Mixed and Other groups (£3,333 and £3,027, respectively). Medians were £0 across groups, but the mean differences indicate variation in the intensity of hospital use once individuals are admitted

## Deprivation

Mean hospital costs rose from £2,859 in the least deprived areas to £3,448 in the most deprived, indicating that people with dementia living in more deprived communities are more likely to require intensive and costly inpatient care (**Figure 6**)

**Figure 6. Median hospital care costs by deprivation level**



## Urban-rural context

Mean hospital costs were higher in urban areas (£3,112) than in rural settings (£2,732), which may reflect closer proximity to acute hospitals, differences in admission thresholds, or unequal availability of community-based alternative.

## Regional variation

Regional variation was even more marked: London recorded the highest mean hospital costs at £3,557, followed by the South East (£3,195), whereas lower costs were observed in the South West (£2,656) and North East (£3,062). These patterns point to differences in resource availability, hospital capacity, case mix, and local models of dementia care.

While the matched sample showed some broadly similar gradients—such as higher costs in more deprived areas and higher costs in London—its overall cost levels were consistently much lower across all groups. This reinforces that dementia itself is a major driver of increased hospital spending, rather than demographic or regional factors alone.

## Next Steps

Work is under way to complete the remaining components of the project so that the final report can provide a fully integrated picture of dementia care utilisation and inequalities.

### 1. Write-up of the consultation findings

We are finalising the analysis and synthesis of insights from the public and patient involvement and engagement (PPIE) activities. These consultations provide essential qualitative context to the quantitative findings, offering lived-experience perspectives on where the system works or fails after diagnosis.

### 2. Finalise the review of reviews

The umbrella review synthesising existing UK and international evidence on **inequalities in dementia care**, including access, utilisation, and outcomes across demographic and geographic groups, is being finalised. Data extraction is almost completed, and we will be writing up the findings shortly.

This review will:

- map the strength and consistency of evidence on inequalities across the care pathway,
- identify which inequalities have the strongest evidence base and where gaps remain,
- situate the findings of this interim study within the broader literature,
- and highlight areas where further research or targeted intervention is most justified.

The final version will be integrated into the concluding report, ensuring that the study's recommendations draw on both new empirical evidence and established research.

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## Appendices

### Appendix 1. Number of primary care contacts 12 months post-diagnosis in people living with dementia and in the age/sex/region matched sample

|             |                          | Dementia<br>(n=20906) |             | Matched Sample<br>(n=20905) |             |
|-------------|--------------------------|-----------------------|-------------|-----------------------------|-------------|
|             |                          | Median<br>(IQR)       | Mean (SD)   | Median (IQR)                | Mean (SD)   |
| Overall     |                          | 13.0 (13.0)           | 14.9 (10.8) | 7.0 (10.0)                  | 9.6 (9.1)   |
| Age         | 80+                      | 13.0 (12.0)           | 15.0 (10.7) | 8.0 (10.0)                  | 10.2 (9.6)  |
|             | 75-79                    | 13.0 (12.0)           | 14.9 (10.6) | 7.0 (10.0)                  | 9.5 (8.8)   |
|             | 70-74                    | 12.0 (13.0)           | 14.7 (11.4) | 7.0 (9.0)                   | 8.5 (7.7)   |
|             | 65-69                    | 13.0 (13.0)           | 15.1 (11.0) | 6.0 (9.0)                   | 7.6 (7.0)   |
|             | <65                      | 12.0 (12.0)           | 14.4 (10.9) | 5.0 (7.0)                   | 6.6 (7.1)   |
| Sex         | Male                     | 13.0 (12.0)           | 14.9 (10.5) | 7.0 (10.0)                  | 9.4 (9.6)   |
|             | Female                   | 13.0 (13.0)           | 15.0 (11.0) | 8.0 (11.0)                  | 9.7 (9.3)   |
| Ethnicity   | White                    | 12.0 (13.0)           | 14.8 (10.7) | 8.0 (10.0)                  | 10.7 (9.2)  |
|             | Asian                    | 16.0 (13.0)           | 18.3 (11.8) | 11.0 (11.0)                 | 12.6 (9.1)  |
|             | Black                    | 15.0 (14.0)           | 17.2 (10.8) | 12.0 (12.0)                 | 13.1 (9.7)  |
|             | Mixed                    | 13.5 (10.0)           | 14.9 (9.7)  | 8.0 (8.0)                   | 9.1 (7.0)   |
|             | Other                    | 14.0 (15.0)           | 16.3 (11.0) | 9.0 (9.5)                   | 10.7 (8.1)  |
| Deprivation | Missing                  |                       |             |                             |             |
|             | 1 (least)                | 12.0 (13.0)           | 14.7 (10.5) | 8.0 (10.0)                  | 10.2 (9.0)  |
|             | 2                        | 12.0 (13.0)           | 14.8 (10.9) | 8.0 (10.0)                  | 10.0 (9.0)  |
|             | 3                        | 13.0 (13.0)           | 14.9 (10.3) | 8.0 (10.0)                  | 10.2 (8.8)  |
|             | 4                        | 13.0 (12.0)           | 15.4 (11.4) | 8.0 (10.0)                  | 10.2 (9.3)  |
| Urban/rural | 5 (most)                 | 12.0 (12.5)           | 15.0 (10.9) | 8.0 (10.0)                  | 10.0 (9.2)  |
|             | Missing                  |                       |             |                             |             |
|             | Urban                    | 13.0 (13.0)           | 14.9 (10.7) | 7.0 (10.0)                  | 9.6 (9.1)   |
|             | Rural                    | 13.0 (12.0)           | 15.3 (11.3) | 8.0 (9.0)                   | 9.8 (9.1)   |
|             | Missing                  |                       |             |                             |             |
| Region      | South East               | 13.0 (12.0)           | 15.3 (11.1) | 8.0 (11.0)                  | 10.0 (10.0) |
|             | North East               | 11.0 (9.0)            | 12.3 (8.3)  | 7.0 (9.0)                   | 8.7 (7.6)   |
|             | North West               | 12.0 (12.0)           | 13.8 (10.0) | 7.0 (10.0)                  | 9.0 (8.4)   |
|             | Yorkshire and the Humber | 13.0 (13.0)           | 14.7 (10.1) | 8.0 (10.0)                  | 9.9 (9.0)   |
|             | East Midlands            | 12.0 (13.0)           | 14.6 (10.9) | 8.0 (11.0)                  | 10.3 (9.9)  |
|             | West Midlands            | 12.0 (12.0)           | 14.1 (10.5) | 7.0 (10.0)                  | 9.4 (8.7)   |
|             | East of England          | 13.0 (12.0)           | 15.2 (10.4) | 7.0 (9.0)                   | 9.1 (8.8)   |
|             | London                   | 14.0 (14.0)           | 16.8 (11.6) | 8.0 (11.0)                  | 10.1 (9.1)  |
|             | South West               | 14.0 (13.0)           | 16.1 (11.3) | 8.0 (10.0)                  | 10.1 (9.6)  |

## Appendix 2. Number of hospitalisations 12 months post-dementia diagnosis and in the age/sex/region matched sample

|             |                          | <b>Dementia<br/>(N=26544)</b> |            | <b>Matched sample<br/>(N=17769)</b> |           |
|-------------|--------------------------|-------------------------------|------------|-------------------------------------|-----------|
|             |                          | Median<br>(IQR)               | Mean (SD)  | Median (IQR)                        | Mean (SD) |
| Overall     |                          | 0.0 (1.0)                     | 1.1 (3.4)  | 0.0 (1.0)                           | 0.6 (2.2) |
| Age         | 80+                      | 1.0 (2.0)                     | 1.1 (3.3)  | 0.0 (1.0)                           | 0.7 (2.1) |
|             | 75-79                    | 0.0 (1.0)                     | 1.0 (2.8)  | 0.0 (1.0)                           | 0.6 (1.9) |
|             | 70-74                    | 0.0 (1.0)                     | 1.1 (4.4)  | 0.0 (1.0)                           | 0.6 (3.4) |
|             | 65-69                    | 0.0 (1.0)                     | 1.1 (2.7)  | 0.0 (0.0)                           | 0.4 (1.1) |
|             | <65                      | 0.0 (1.0)                     | 1.2 (5.2)  | 0.0 (0.0)                           | 0.4 (1.3) |
| Sex         | Male                     | 1.0 (2.0)                     | 1.2 (3.9)  | 0.0 (1.0)                           | 0.7 (1.9) |
|             | Female                   | 0.0 (1.0)                     | 1.0 (3.0)  | 0.0 (1.0)                           | 0.6 (2.4) |
| Ethnicity   | White                    | 0.0 (1.0)                     | 1.1 (3.0)  | 0.0 (1.0)                           | 0.7 (2.0) |
|             | Asian                    | 0.0 (1.0)                     | 1.0 (1.6)  | 0.0 (1.0)                           | 0.5 (1.0) |
|             | Black                    | 0.0 (1.3)                     | 1.9 (10.1) | 0.0 (1.0)                           | 1.3 (8.8) |
|             | Mixed                    | 1.0 (2.0)                     | 1.3 (3.5)  | 0.0 (0.0)                           | 0.5 (1.4) |
|             | Other                    | 0.0 (1.0)                     | 1.5 (8.8)  | 0.0 (1.0)                           | 0.6 (1.8) |
|             | Missing                  |                               |            |                                     |           |
| Deprivation | 1 (least)                | 0.0 (1.0)                     | 1.0 (2.4)  | 0.0 (1.0)                           | 0.7 (3.3) |
|             | 2                        | 0.0 (1.0)                     | 1.0 (3.0)  | 0.0 (1.0)                           | 0.6 (1.3) |
|             | 3                        | 0.0 (1.0)                     | 1.1 (3.4)  | 0.0 (1.0)                           | 0.6 (2.0) |
|             | 4                        | 0.0 (1.0)                     | 1.2 (4.9)  | 0.0 (1.0)                           | 0.6 (1.6) |
|             | 5 (most)                 | 1.0 (2.0)                     | 1.2 (3.3)  | 0.0 (1.0)                           | 0.7 (1.6) |
|             | Missing                  |                               |            |                                     |           |
| Urban/rural | Urban                    | 0.0 (2.0)                     | 1.1 (3.6)  | 0.0 (1.0)                           | 0.7 (2.3) |
|             | Rural                    | 0.0 (1.0)                     | 0.9 (2.3)  | 0.0 (1.0)                           | 0.6 (1.5) |
|             | Missing                  |                               |            |                                     |           |
| Region      | South East               | 0.0 (1.0)                     | 1.0 (2.5)  | 0.0 (1.0)                           | 0.7 (2.5) |
|             | North East               | 1.0 (2.0)                     | 1.1 (1.7)  | 0.0 (1.0)                           | 0.6 (1.3) |
|             | North West               | 0.0 (1.0)                     | 1.1 (3.8)  | 0.0 (1.0)                           | 0.7 (1.9) |
|             | Yorkshire and the Humber | 0.0 (1.0)                     | 0.9 (1.5)  | 0.0 (1.0)                           | 0.6 (1.3) |
|             | East Midlands            | 0.0 (1.0)                     | 1.0 (1.7)  | 0.0 (1.0)                           | 0.7 (1.5) |
|             | West Midlands            | 0.0 (2.0)                     | 1.1 (3.7)  | 0.0 (1.0)                           | 0.7 (2.1) |
|             | East of England          | 0.0 (2.0)                     | 1.1 (1.8)  | 0.0 (1.0)                           | 0.6 (1.4) |
|             | London                   | 1.0 (2.0)                     | 1.4 (5.0)  | 0.0 (1.0)                           | 0.8 (3.5) |
|             | South West               | 0.0 (1.0)                     | 0.9 (3.0)  | 0.0 (1.0)                           | 0.5 (1.3) |

### Appendix 3. Primary care costs (GBP) 12 months post-dementia diagnosis and in the age/sex/region matched sample

|             |                          | <b>Dementia</b> | <b>Matched sample</b> |
|-------------|--------------------------|-----------------|-----------------------|
|             |                          | Median (IQR)    | Median (IQR)          |
| Overall     |                          | 272 (296)       | 147 (217)             |
| Age         | 80+                      | 280 (281)       | 162 (233)             |
|             | 75-79                    | 266 (284)       | 147 (203)             |
|             | 70-74                    | 250 (271)       | 126 (189)             |
|             | 65-69                    | 267 (291)       | 108 (170)             |
|             | <65                      | 247 (280)       | 89 (154)              |
| Sex         | Male                     | 270 (287)       | 144 (207)             |
|             | Female                   | 273 (301)       | 151 (222)             |
| Ethnicity   | White                    | 270 (294)       | 170 (216)             |
|             | Asian                    | 322 (307)       | 205 (237)             |
|             | Black                    | 326 (303)       | 216 (261)             |
|             | Mixed                    | 294 (258)       | 125 (188)             |
|             | Other                    | 288 (350)       | 181 (205)             |
| Deprivation | Missing                  |                 |                       |
|             | 1 (least)                | 272 (297)       | 162 (212)             |
|             | 2                        | 270 (297)       | 158 (209)             |
|             | 3                        | 272 (294)       | 159 (220)             |
|             | 4                        | 276 (293)       | 158 (212)             |
| Urban/rural | 5 (most)                 | 271 (296)       | 150 (220)             |
|             | Missing                  |                 |                       |
|             | Urban                    | 270 (294)       | 146 (216)             |
|             | Rural                    | 290 (302)       | 155 (218)             |
|             | Missing                  |                 |                       |
| Region      | South East               | 275 (289)       | 153 (220)             |
|             | North East               | 231 (246)       | 138 (201)             |
|             | North West               | 254 (293)       | 141 (203)             |
|             | Yorkshire and the Humber | 271 (267)       | 144 (207)             |
|             | East Midlands            | 265 (296)       | 161 (217)             |
|             | West Midlands            | 257 (286)       | 146 (218)             |
|             | East of England          | 282 (298)       | 147 (217)             |
|             | London                   | 314 (327)       | 163 (246)             |
|             | South West               | 291 (295)       | 144 (209)             |

## Appendix 4. Hospital care costs (GBP) 12 months post-dementia diagnosis and in the age/sex/region matched sample

|             |                          | Dementia (N=25899) |             | Matched sample (N=17769) |             |
|-------------|--------------------------|--------------------|-------------|--------------------------|-------------|
|             |                          | Median (IQR)       | Mean (SD)   | Median (IQR)             | Mean (SD)   |
| Overall     |                          | 0 (3870)           | 3058 (5756) | 0 (978)                  | 1387 (3791) |
| Age         | 80+                      | 0 (4258)           | 3250 (5934) | 0 (1285)                 | 1501 (3851) |
|             | 75-79                    | 0 (3489)           | 2829 (5432) | 0 (768)                  | 1306 (3995) |
|             | 70-74                    | 0 (3040)           | 2729 (5378) | 0 (674)                  | 1183 (3656) |
|             | 65-69                    | 0 (2804)           | 2685 (5776) | 0 (0)                    | 917 (2653)  |
|             | <65                      | 0 (2044)           | 2222 (4963) | 0 (0)                    | 665 (2650)  |
| Sex         | Male                     | 302 (4221)         | 3287 (6119) | 0 (1023)                 | 1494 (4078) |
|             | Female                   | 0 (3617)           | 2904 (5492) | 0 (952)                  | 1315 (3582) |
| Ethnicity   | White                    | 0 (3957)           | 3090 (5807) | 0 (907)                  | 1428 (3854) |
|             | Asian                    | 0 (2878)           | 2514 (4717) | 0 (0)                    | 1128 (2997) |
|             | Black                    | 0 (3494)           | 2972 (5743) | 0 (0)                    | 1711 (4768) |
|             | Mixed                    | 0 (4306)           | 3333 (5798) | 0 (0)                    | 841 (2456)  |
|             | Other                    | 0 (3719)           | 3027 (5293) | 0 (1023)                 | 1286 (3288) |
|             | Missing                  |                    |             |                          |             |
| Deprivation | 1 (least)                | 0 (3560)           | 2859 (5308) | 0 (880)                  | 1388 (3942) |
|             | 2                        | 0 (3587)           | 2880 (5323) | 0 (1038)                 | 1402 (3622) |
|             | 3                        | 0 (3798)           | 3050 (5629) | 0 (808)                  | 1284 (3580) |
|             | 4                        | 0 (4115)           | 3216 (6453) | 0 (1023)                 | 1479 (4075) |
|             | 5 (most)                 | 484 (4491)         | 3448 (6271) | 0 (1023)                 | 1397 (3718) |
|             | Missing                  |                    |             |                          |             |
| Urban/rural | Urban                    | 0 (4020)           | 3112 (5832) | 0 (993)                  | 1404 (3852) |
|             | Rural                    | 0 (3284)           | 2732 (5264) | 0 (808)                  | 1304 (3469) |
|             | Missing                  |                    |             |                          |             |
| Region      | South East               | 0 (3769)           | 3195 (6401) | 0 (987)                  | 1429 (3912) |
|             | North East               | 0 (4007)           | 3062 (5276) | 0 (821)                  | 1201 (3362) |
|             | North West               | 0 (3749)           | 2918 (5232) | 0 (1023)                 | 1342 (3701) |
|             | Yorkshire and the Humber | 0 (4097)           | 3162 (5813) | 0 (689)                  | 1471 (3883) |
|             | East Midlands            | 0 (3496)           | 2719 (5109) | 0 (1281)                 | 1911 (4553) |
|             | West Midlands            | 0 (3510)           | 2924 (5883) | 0 (901)                  | 1284 (3390) |
|             | East of England          | 0 (4063)           | 3334 (5886) | 0 (1018)                 | 1629 (4764) |
|             | London                   | 302 (4617)         | 3557 (6162) | 0 (1131)                 | 1602 (4188) |
|             | South West               | 0 (3496)           | 2656 (4860) | 0 (768)                  | 1199 (3361) |

Thank you for reading the report. Our contact details can be found below.

 [denpru@exeter.ac.uk](mailto:denpru@exeter.ac.uk)

 [denpruexeter.nihr.ac.uk](http://denpruexeter.nihr.ac.uk)

 [@denpruexeter.bsky.social](https://bsky.app/profile/denpruexeter.bsky.social)