What gets recorded, counts: Dementia recording in primary care compared with a specialist database

Katrina A. S. Davis[a,b]
Christoph Mueller[a,b]
Mark Ashworth[c]
Matthew Broadbent[b]
Amelia Jewel[b]
Mariam Molokhia[c]
Gayan Perera[a,b]
Robert J. Stewart[a,b]

[a]*King's College London Institute of Psychiatry Psychology and Neuroscience, London, UK*

[b]*South London and Maudsley NHS Foundation Trust, London, UK*

[c]*King's College London Population Health Sciences, London, UK*

Corresponding author: Katrina AS Davis

Affiliations: *King's College London Institute of Psychiatry, Psychology and Neuroscience & South London and Maudsley NHS Foundation Trust*

Postal address: Psychological Medicine, 3rd Floor East Corridor, Main KCL IoPPN Building, De Crespigny Park, Denmark Hill, London, UK, SE5 8AF

Email: katrina.davis@kcl.ac.uk

Abstract

Background: Databases of electronic health records are powerful tools for dementia research, but data can be influenced by incomplete recording. We examined whether people with dementia recorded in a specialist database (from a mental health and dementia care service) differ from those recorded in primary care.

Methods: A retrospective cohort study of the population covered by Lambeth DataNet (primary care electronic records) between 2007 and 2019. Documentation of dementia diagnosis in primary care coded data and linked records in a specialist database (Clinical Records Interactive Search, CRIS) were compared.

Results: 3859 people had dementia documented in primary care codes and 4266 in the specialist database, with 2886/5239 (55%) documented in both sources. Overall, 55% were labelled as having Alzheimer's dementia and 29% were prescribed dementia medication, but these proportions were significantly higher in those documented in both sources. The cohort identified from the specialist database were less likely to live in a care home (prevalence ratio 0.73, 95% confidence interval 0.63-0.85), have multimorbidity (0.87, 0.77-0.98) or consult frequently (0.91, 0.88-0.95) than those identified through primary care codes, although mortality did not differ (0.98, 0.91-1.06).

Discussion: There is under-recording of dementia diagnoses in both primary care and specialist databases. This has implications for clinical care and for generalizability of research. Our results suggest that using a mental health database may under-represent those patients who have more

frailty, reflecting differential referral to mental health services, and demonstrating how the patient pathways are an important consideration when undertaking database studies.

Key words: Dementia, Electronic Health Records, Primary Care, cohort studies, older people.

Key points:

- There is evidence of under-documentation of dementia in both primary care and specialist care
- Data from specialist providers may under-represent those with complex needs
- Data from primary care may over-represent those who are prescribed dementia medication
- Under-documentation may lead to less optimal clinical care and indicates possible problems in equity of care

Introduction

The complexity and heterogeneity of dementia means that many of the remaining research questions relating to dementia and dementia care cannot be answered by conventional means, such as randomised controlled trials. Healthcare database studies offer excellent opportunities. Many utilise electronic health records (EHR) to capture key demographic and clinical data, such as diagnostic codes, referrals, and prescribing (1-3). However, findings in healthcare databases may be influenced by where in the patient care pathway the data is collected (4, 5). If such databases are used they may not be representative of the full population of people living with dementia, particularly in terms of clinical features. This can affect the generalisability of the findings or even the results themselves, for instance extrapolation of prevalence or absolute risk (6, 7).

In the UK, the main pathway to a dementia diagnosis, and treatment with acetylcholinesterase inhibitors for those with Alzheimer's type dementia, is assessment in primary care followed by referral to a specialist dementia diagnostic service, often either in community mental health services or memory clinics provided by mental health services (8). Brayne and Davis's (6) review of sources of data for research in dementia suggests that, compared with data from primary care, data from specialist services (mental health and memory clinic providers) will tend to over-represent those who have "memory problems" but are otherwise "relatively fit". This study takes advantage of linked primary care EHR and specialist EHR databases to explore the degree of overlap between the cohorts of people with recorded dementia in each data source, and thus the extent of under-documentation. We explore whether the character of patients in those cohorts reflect the patient pathway such that, compared to primary care, those with dementia diagnosis in the specialist database are (i) less likely to have markers of frailty and complexity (ii) more likely to have Alzheimer's-type dementia and be prescribed dementia medication.

Methods:

A retrospective cohort study where the cohort was patients registered with a Lambeth GP any time in the years 2007-2019, utilising linkage to a specialist database.

Databases

Lambeth DataNet (LDN) provided data from primary care. LDN collects structured data from the electronic health records of all GP surgeries in the borough of Lambeth (9). A person with a record in LDN will have had some contact with a Lambeth GP practice, which does not require residence in Lambeth.

South London and Maudsley NHS Foundation Trust (SLaM) provides specialist mental health and dementia care services for four London boroughs (Lambeth, Southwark, Lewisham and Croydon) (10). Data from SLaM feed into a bespoke database of de-identified records through the infrastructure and oversight arrangements of the Clinical Records Interactive Search (CRIS), which can then be linked to other local and national data sources (10). This allows the opportunity of utilising data from detailed assessments, such as those provided in memory clinics, alongside important outcomes recorded elsewhere, such as admission to general hospitals and death (11-13).

The CRIS/LDN linkage is conducted by the CRIS data-linkage service (10). CRIS, including linkage to Lambeth DataNet, has received ethical approval as an anonymized data resource (Oxford Research Ethics Committee C, reference 18/SC/0372). This project was approved by the CRIS oversight committee. Code lists used are in Appendix 1 (ST1-6).

Cohort

Our population was the 1.2 million people with an LDN health records between 2007 and 2019. This means we only included people who were registered with a Lambeth GP, and we included them whether or not they had a record in secondary care. We defined dementia documentation from the structured fields of the respective databases. CRIS contained ICD-10 diagnostic codes, from which we selected codes referring to dementia from the mental and behavioural disorder chapter (F00-03); LDN had Read codes and SNOMED clinical terminologies following the recent national change in preferred ontology (14). The Read code list ascertaining dementia replicated that from the SAIL-Dementia eCohort (15) and SNOMED codes were derived from those lists using the NHS mapping file (16). By review of the English terms attached to the Read and SNOMED Concept terms we allocated them into 'high specificity' (e.g. "Unspecified dementia"), which were sufficient on their own to indicate a diagnosis of dementia, and 'low specificity' (e.g. "Delirium superimposed on dementia") that required supporting codes (Appendix 1, ST1).

Inclusion criteria for our main cohort were:
(1) Record for patient aged at least 18 years in LDN between 01/01/2007 to 31/05/2019
AND
(2a) Dementia code in CRIS (ICD-10 diagnosis fields) between 01/01/2007 and 31/05/2019
OR
(2b) Dementia code(s) in LDN (Read or SNOMED code): either one from the ‘high specificity’ list or two different codes from the ‘low specificity’ list (ST1) with an effective date between 01/01/2007 and 31/05/2019
AND
(3) The first recorded dementia date (recorded date for CRIS, effective date for LDN) occurred when aged 65 years or more

Cohort Characteristics

We extracted year of birth, gender and ethnicity from LDN. When describing the denominator of people aged above 65 in LDN, we included all those with age 65 or above at the median diagnosis date of those in LDN with a diagnosis of dementia (24/05/2013). Ethnicity was assigned within LDN as 16 classes, from which we used White British unchanged as the reference class, and condensed ethnicities that may be subject to disadvantage into White non-British, Black (Black and Black British), Asian (Asian and Asian British), Mixed and Other (Chinese and Any other). LDN gives last known address at the level of Lower Super Output Areas (LSOA, a standard geographic unit with an average population of 1700), which allowed us to calculate a neighbourhood measure of deprivation (Index of Multiple Deprivation, IMD) using publicly available data tables (17). For sensitivity analyses we also ascertained whether a patient lived in Lambeth and whether they had at least one consultation documented in LDN on or prior to the data of the first documentation of dementia, which we term "prior consultation".

Selected health indices were extracted from LDN for dates prior to the first documentation of dementia: number of GP consultations in the previous two years (Appendix 1:3), smoking status (Appendix 1:4), and comorbidity score. The comorbidity score was a modified Charlson comorbidity index that used SNOMED codes for chronic conditions adapted from Read code lists developed for the CALIBER project (18) converted using the NHS mapping file (16) and summed with weights from Quan et al.(19) (excluding dementia, Appendix 1:5). Care home residence was indicated by any care home visit in consultation type in the two years before diagnosis.

The subtype of dementia was determined from CRIS, where possible, taking the most recent ICD-10 dementia diagnosis. Where dementia was identified in LDN only, Read/SNOMED codes that represented specific dementia subtypes were extracted from LDN (Appendix 1:2) and the most frequent subtype was allocated. Unspecified subtype was allocated where dementia was categorised as unspecified in CRIS, or no subtype codes were used in LDN. Dementia medication was defined as acetylcholinesterase inhibitors or memantine (Appendix 1:6) prescribed at least once in LDN.

Analysis:
Prevalence and patterns of missing data were explored. Descriptive statistics were calculated in MS Excel and R version 3.5.1. Confidence intervals are given around at 95% confidence (using Wilson's method for proportions and binomial method for prevalence ratio). Proportions are given to the nearest percentage point unless <10%. Chi-squared tests were used to compare characteristics where we had specific hypotheses.

Results:
Of patients with a LDN record between 2007 and 2019 aged 65 or over, 3859 had dementia codes in primary care, with a median of two different codes from the list in Appendix 1 (interquartile range 1-7 different codes). 4266 had dementia documented in the specialist care database. Combining the two sources of documentation found 5239 unique patients with documented dementia in either source, making up 0.45% of all adult LDN patients or 5.4% of those over 65. This is our main cohort for analysis. Fifty-five percent of people identified with dementia were identified by both primary care codes and specialist database (2886/5239), as shown in Figure 1. 75% of those identified by primary care codes were also identified by the specialist database, and 68% of those identified by the specialist database were also identified by primary care codes. Of those identified, 84% resided in Lambeth and 85% had a prior GP consultation. Figure 1 shows the effect on overlap of restricting to these subpopulations and with a date restriction allowing for longer follow-up. Restricting the sample by residence or prior consultation modestly increased the percentage overlap in documentation from 55% to 57% (by residence, see also Appendix 2) or 60% (by prior consultation). Appendix 2 shows that both the number of cases per year and the proportion of primary care recording was highest in the years 2011-2015.

Figure 1 ***Documentation of dementia in specialist database, primary care codes or both for main cohort and subpopulations***

Characteristics of the main cohort are shown in Appendix 3. Three variables from LDN were found to contain missing data: ethnicity (744/5239, 14%), smoking status (652/5239, 12%), and LSOA/address (111/5239, 2%). Restricting to those living in Lambeth made little difference, but prior consultation reduced the risk of missing data. Dividing the cohort into exclusive groups of those identified by both primary care codes and the specialist database ('both', n = 2886), those identified by the specialist database only (n = 1380) and those with primary care codes only (n = 973), levels of missing data were higher for people in the specialist only group. Table 1 and 2 show proportions excluding missing data, while Appendix 4 shows the equivalent with missing data or restricting by prior consultation.

Table 1 shows the demographic features of the three documentation groups. The three documentation groups had similar age, sex and deprivation distribution, but ethnicity differed, with under-representation of documented Black ethnicity in those in the specialist only group. Table 2 displays the outcome of tests on the hypothesis that there was a difference between the groups on

measures of frailty or complexity. A significant difference was found in all three-way comparisons ($p<0.001$). The specialist-only group had lower Charlson comorbidity index, lower numbers of prior consultations and fewer care home consultations. The primary care only group had the highest mortality. Restricting to people who had consulted primary care in the two years prior to diagnosis (Appendix 4) reduced but did not abolish the differences.

Table 2 also shows that those with documentation in both databases were more commonly recorded with Alzheimer's type dementia and less commonly documented as having "unspecified" or vascular dementia than those with only one type of documentation. 29% (1505/5239) of patients were prescribed dementia medications in primary care, and this varied from 41% in those documented in both sources to 8% in the specialist only group. Among those prescribed dementia medication, 93% had primary care codes for dementia.

Table 1 Demographics of individuals in Lambeth DataNet in strata representing the ascertainment of dementia from two sources, specialist database and primary care codes

Table 1 Clinical characteristics of individuals in Lambeth DataNet in strata representing the ascertainment of dementia from two sources, specialist database and primary care codes

Comparing the overlapping samples of the LDN cohort that could have been generated from the specialist database (combining 'specialist only' and 'both' from Table 1, n = 3859) and primary care codes (combining 'primary care only' and 'both', n = 4266), Table 3 shows the specialist database sample had significantly lower proportions of White British ethnicity, lower consultation rates, lower multimorbidity and fewer in care homes – but with fairly small effect size (prevalence ratios 0.94, 0.91, 0.85, 0.73 respectively). There was no difference in mortality (prevalence ratio 0.98, 0.91-1.06). The specialist database sample are also less likely to have been prescribed dementia medication (prevalence ratio 0.85, 0.80-0.91), explored further in Appendix 5, which shows the largest discrepancy in being prescribed medication was in those with Alzheimer's type dementia.

Table 3: Comparison of characteristics of individuals in Lambeth DataNet in two overlapping cohorts: Dementia documented in specialist database; and Dementia codes in primary care.

Discussion:

We investigated the likely generalisability of findings made from databases of routinely recorded healthcare data by assessing patient characteristics associated with cohorts derived from two methods of ascertaining dementia cases in a defined population: structured diagnosis in a specialist mental health dementia service and coded documentation in primary care. We identified 5239 patients with eligible dementia documentation, 55% of whom were documented in both data sources, 26% only in specialist care and 19% only in primary care. Those with dementia documented in the speciality database were less likely to live in a care home, consult the GP less frequently and have fewer comorbidities than those with dementia documented in the primary care codes. It therefore seems likely that the specialist database under-reflects frail and complex patients. Perhaps surprisingly, those in the specialist database were not more likely to have Alzheimer's dementia and they were less likely to be prescribed dementia medication.

Both NICE guidelines and the primary care services contract emphasise the need for full memory clinic assessment in most cases when dementia is suspected, and that the clinic will assess for suitability for medication (8, 20), which led to our hypothesis that we would see over-representation of those prescribed dementia medication in the specialist database. However, 93% of those prescribed dementia medication had primary care coding, compared with 66% of those not prescribed dementia medication. This may be due to reverse causation – those patients prescribed dementia medications by their GP subsequently get coded with dementia. Those without diagnosis in the specialist database, some of whom were prescribed dementia medications, might reflect diagnosis in other places such as elderly care clinics (not included in our data-source), which may be deemed more appropriate if patients had a mixture of physical and cognitive difficulties.

Of the people with dementia documented in the specialist database, 32% did not have this formally documented in primary care; this despite pressure on GPs to recognise possible dementia, refer, and document diagnosis (20). Our work is consistent with others in that primary care documentation increased in 2011-2015 when specific funding was available for dementia case finding (21-23), but that gaps in documentation remain. For example comparing general hospital statistics with primary care codes has shown proportions of cases with a dementia diagnosis on their hospital data that did not have this recorded in primary care was 44% in an English sample (24) and 39% in Wales (15). Severity is thought to be a predictor of documentation in primary care (13, 25), to which we can add prescription of dementia medication. Our results suggest that White British people are more likely to have primary care codes than those of Black ethnicity – although our study was not looking at this, and so the finding should be regarded as tentative. Some under-ascertainment may occur when people move in and out of areas (for example to enter a care home), as GP practices in the UK each have their own electronic records that may not move with the patient or integrate with other IT systems. Under-documentation is a barrier to good clinical care (12, 26). Initiatives are consequently being developed to integrate care records to ensure clinicians have the information they need wherever the patient presents (27, 28).

Under-documentation will have obvious repercussions on estimating the prevalence of diagnosed dementia, but a lack of sensitivity has wider consequences for research (29). Unless a source of dementia diagnosis is near-complete, identification of people with dementia using this documentation will reflect patient and system factors that influenced the documentation, with risk of misclassification in the study. Our findings indicate that when patients with dementia are selected using single agency data the cohort may not be fully representative in both demographics and clinical characteristics. Conversely, these findings may indicate that the patient pathways themselves are not delivering equity of access.

Strengths and limitations

To our knowledge, this is the first study to compare dementia recorded in primary and specialist care in the UK. While the exact findings may not be generalisable elsewhere (especially due to the populations served in this catchment (10)), we expect the observations about under-documentation will be widely applicable. We used previously applied code lists to maximise the applicability of findings; however, limiting to coded data may have under-ascertained dementia documented as free-text. For comorbidities, we took lack of documentation to mean absence of condition, but they will be subject to the same under-documentation biases as we describe for dementia. For prescribing, we are assuming that specialist services always asked primary care to prescribe dementia medications (as was the policy), but there may have been patients who received it directly. Our inclusion criteria included people who were registered with a GP practice in Lambeth

for only part of the date window, which may have accounted for another portion of under-ascertainment. Including more data sources to our search (such as from general hospitals in the area) may have increased the number of individuals we identified, and would be likely to show more under-documentation.

Any documentation of dementia that met our criteria was taken to represent a true positive case of dementia, but the code lists and our algorithm have not been externally validated against a clinical assessment. Given the relatively high prevalence of dementia in older adults and the known problem of under-documentation (5) we assume that false negatives are more likely than false positives as a cause for lack of overlap, but it is likely that there are also cases of mistakes in documentation. We are also conscious that the documentation gap we have demonstrated is related, but separate to, the diagnosis gap. To fully understand the under-documentation for people with dementia, we would need to include a cohort screened for dementia to identify those without diagnosis.

Conclusions and implications

Documentation in EHR is important for clinical care and secondary use for database research studies. We found that two EHR databases for the same population sample found broadly equal numbers of people documented as living with dementia with substantial, but incomplete, overlap in the people identified. This incomplete documentation may suggest some inequality of access, which deserves further investigation. Researchers and clinicians using healthcare databases should be aware that where they cover only some of the real-life patient pathways, they may miss a proportion of people with dementia, and take this into account when choosing databases and interpreting the results. Opportunities for data linkage drawing from multiple databases will improve the generalisability of findings.

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Code availability: Full code lists for extraction are available as a dataset [dataset] Davis, Ma & Polling, 2021, Appendix1 code lists, Code lists used for linked Lambeth DataNet - CRIS linked project: Dementia cohorts, ResearchGate. DOI: 10.13140/RG.2.2.14629.42729

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Figures:
Figure 1: Bar chart showing the overlap of people in Lambeth DataNet identified through using linkage to a specialist mental health database and those identified through primary care codes.

Tables:
Table 1 Demographics of individuals in Lambeth DataNet in strata representing the ascertainment of dementia from two sources, specialist database and primary care codes
Table 2 Clinical characteristics of individuals in Lambeth DataNet in strata representing the ascertainment of dementia from two sources, specialist database and primary care codes
Table 3 Comparison of characteristics of individuals in Lambeth DataNet in two overlapping cohorts: Dementia documented in specialist database; and Dementia codes in primary care

Supplemental material:
Appendix 1: Tables ST1-6: Code lists etc.
Appendix 2: Table A2: Proportion of people with dementia identified by two sources looking over time and by Lambeth residence.
Appendix 3: Table A3: Characteristics and missing data for main cohort from Lambeth DataNet, compared against those also with Lambeth residence
Appendix 4: Table A4 (A-C) Characteristics of patients with dementia documented in either specialist database or primary care database or both. A: Excluding missing data, B: Including missing data, C: Restricting to those patients with prior consultation
Appendix 5: Table A5 and Figure A5 Proportions of LDN patients identified with dementia prescribed dementia medication in primary care broken down by source of documentation and subtype of dementia.

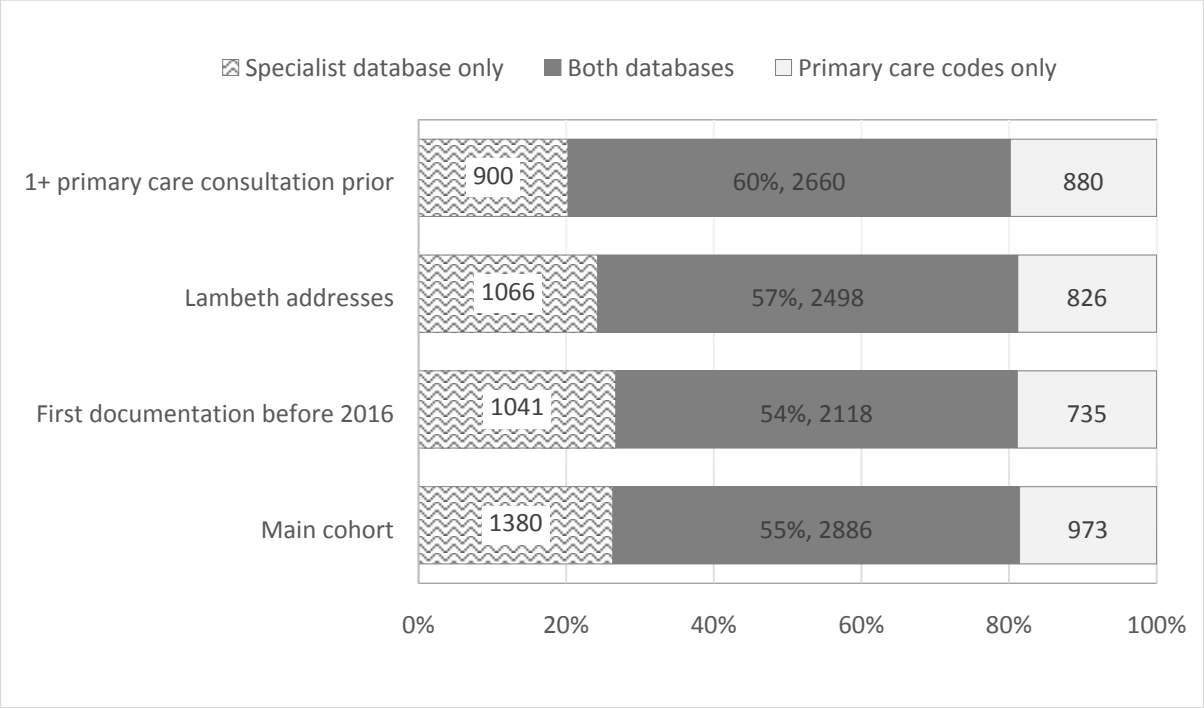


Figure 1: Bar chart showing the overlap of people in Lambeth DataNet identified through using linkage to a specialist mental health database and those identified through primary care codes.
Results for the main cohort used in this paper compared to a number of subpopulations: First documentation before 2016 = had either specialist or primary care code between 2007-2015; Lambeth addresses = last known address in Lambeth; 1+ primary care consultations prior = one face-to-face or telephone encounter in primary care in the two years before first specialist or primary care dementia code.

Table 1 Demographics of individuals in Lambeth DataNet in strata representing the ascertainment of dementia from two sources, specialist database and primary care codes

	Both sources	Specialist only	Primary care only
Age group in years (n = 5239)	n = 2880	n = 1380	n = 973
65-74	18% (17-20)	19% (17-22)	22% (19-24)
75-84	47% (45-49)	43% (40-45)	44% (41-47)
85+	34% (33-36)	38% (35-40)	35% (32-38)
Sex (n = 5239)	n = 2880	n = 1380	n = 973
Female	61% (59-63)	57% (55-60)	59% (56-62)
Male	39% (37-41)	43% (40-45)	41% (38-44)
Ethnicity (n = 4495)	n = 2662	n = 925	n = 908
White British	44% (42-46)	51% (48-54)+	45% (42-48)
Black	27% (26-29)	22% (19-25)-	28% (25-31)
White non-British	18% (17-20)	17% (14-19)	15% (13-18)
Asian	5.7% (4.9-6.6)	7.0% (5.6-8.9)	7.2% (5.7-9.0)
Mixed	3.0% (2.5-3.8)	2.8% (1.9-4.1)	3.0% (2.1-4.3)
Other	1.2% (0.8-1.6)	0.6% (0.3-1.4)	2.1% (1.3-3.2)
Missing	omitted	omitted	omitted
Deprivation (IMD[a]) (n = 5128)	n = 2829	n = 1345	n = 954
Quintile 2-5	59% (57-61)	60% (57-63)	60% (57-63)
Quintile 1 (most deprived)	41% (39-43)	40% (37-43)	40% (37-43)
Missing address	omitted	omitted	omitted
Smoking (n = 4589)	n = 2770	n = 878	n = 941
Never	37% (35-38)	43% (40-46)+	37% (34-40)
Former[b]	48% (46-50)	37% (34-40)-	46% (43-49)
Current	15% (14-17)	20% (17-22)	18% (15-20)
Missing	omitted	omitted	omitted

a) IMD = index of multiple deprivation

b) former = documented former smoking or documentation of both smoking and not smoking

"+" = 95% confidence interval above values for those in "both"

"-" = 95% confidence interval below values for those in "both"

Specialist only = Dementia diagnosis in specialist mental health database but no relevant primary care code; Primary care only = Dementia primary care code but no dementia in specialist database; Both = Dementia codes in both specialist database and primary care. Variable n due to exclusion of values that are missing. See table ST7B for inclusion of missing.

Table 2 Clinical characteristics of individuals in Lambeth DataNet in strata representing the ascertainment of dementia from two sources, specialist database and primary care codes

	Both sources	Specialist only	Primary care only
Primary care consultations (n = 5239)[a,c]	n = 2880	n = 1380	n = 973
Above average	59% (57-60)	36% (34-39)-	50% (47-53)-
Average or less	34% (32-35)	29% (27-31)-	41% (38-44)+
None	8% (7-9)	35% (32-37)+	10% (8-12)
	X-squared = 584.77, df = 4, p-value < 0.001		
Care home residence (n = 5239)[a]	n = 2880	n = 1380	n = 973
Yes	8% (7-9)	3% (3-4)-	11% (9-13)
No	92% (91-93)	97% (96-97)+	89% (87-91)
	X-squared = 56.377, df = 2, p-value < 0.001		
Comorbidity index (n = 5239)[a,d]	n = 2880	n = 1380	n = 973
0	31% (30-33)	47% (45-50)+	33% (30-36)
1	22% (20-23)	20% (18-22)	19% (17-22)
2 to 3	34% (33-36)	24% (22-27)-	34% (31-37)
4 to 5	10% (9-12)	7% (6-8)-	11% (9-13)
6+	2.3% (1.8-2.9)	1.7% (1.2-2.6)	3.4% (2.4-4.7)
	X-squared = 121.84, df = 8, p-value < 0.001		
Mortality (n = 5239)[b]	n = 2880	n = 1380	n = 973
No	76% (75-78)	72% (70-75)	69% (66-72)-
Yes	24% (22-25)	28% (25-30)	31% (28-34)+
	X-squared = 20.355, df = 2, p-value < 0.001		
Subtype (n = 4220)	n = 2644	n = 1026	n = 550
Alzheimer's / mixed	74% (73-76)	60% (57-63)-	52% (48-56)-
Vascular	21% (20-23)	34% (31-37)+	41% (37-45)+
Other specified	4.3% (3.6-5.2)	6.0% (4.7-7.7)	7.1% (5.2-9.5)
Unspecified	omitted	omitted	omitted
	X-squared = 139.95, df = 4, p-value < 0.001		
Dementia medication (n = 5239)[b]	n = 2880	n = 1380	n = 973
No	59% (57-61)	92% (91-94)+	77% (74-80)+
Yes	41% (39-43)	8% (6-9)-	23% (20-26)-
	X-squared = 516.79, df = 2, p-value < 0.0001		

Specialist only = Dementia diagnosis in specialist mental health database but no relevant primary care code; Primary care only = Dementia primary care code but no dementia in specialist database; Both = Dementia codes in both specialist database and primary care. Variable n due to exclusion of values that are missing. See table ST7B for inclusion of missing.

a) As documented before the first dementia documentation

b) In the four years post-first dementia documentation, or before June 2019 if earlier

c) Number of face to face and telephone encounters documented in Lambeth DataNet in the two years prior to first dementia documentation. Based on median of 23. Above average = 23+, Below average = 1-22
d) Modified Charlson comorbidity index from primary care-coded morbidities and weights in Quan et al.(19)
"+" = confidence interval above values for those in both
"-" = confidence interval below values for those in both

Table 3 Comparison of characteristics of individuals in Lambeth DataNet in two overlapping cohorts: dementia documented in specialist database; and dementia codes in LDN/primary care

	Prevalence in patients identified by specialist database (+/- primary care codes)		Prevalence in patients Identified by primary care codes (+/- specialty database)		Prevalence ratio – specialist sample : primary care sample
Age group (years): 85+	1516/4266	35.5%	1333/3859	34.5%	1.03 (0.97-1.09)
Sex: Female	2557/4266	59.9%	2340/3859	60.6%	0.99 (0.95-1.02)
Ethnicity: White British	1650/4266	38.7%	1587/3859	41.1%	0.94 (0.89-0.99)
Relative frailty					
Comorbidity high[a]	484/4266	11.3%	503/3859	13.0%	0.87 (0.77-0.98)
Prior consultation high[b]	2190/4266	51.3%	2172/3859	56.3%	0.91 (0.88-0.95)
Care home[c]	270/4266	6.3%	334/3859	8.7%	0.73 (0.63-0.85)
Death during follow-up[d]	1073/4266	25.2%	990/3859	25.7%	0.98 (0.91-1.06)
Subtype					
Alzheimer's / mixed[e]	2577/4266	60.4%	2249/3859	58.3%	1.04 (1.00-1.07)
Dementia medication[f]	1076/3564	30.2%	1176/3324	35.4%	0.85 (0.80-0.91)

a. Scored 4 or more on the modified Charlson comorbidity index (ST5)
b. In two years prior to first dementia diagnosis had face to face or telephone consultation with primary care at or above median number of 23
c. At least one consultation marked as occurring in a care home at any time prior to first dementia diagnosis
d. Death recorded within 4 years of first dementia diagnosis or 31/05/2019 if earlier
e. 86% of those in CRIS cohort and 82% of those in GP cohort had subtype recorded. See appendix 4 for more details.
f Prescribed AChEI or memantine by GP in the four years following first dementia documentation or before June 2019 if earlier.

What gets recorded, counts: Dementia recording in primary care compared with a specialist database

Supplementary Appendices

Contents

Appendix 1: Lists used in study

Code lists used in: What gets recorded, counts: Dementia recording in primary care compared with a specialist database.
Note: 5-byte Read codes used as standard. SNOMED codes allocated using NHS linking file, and should be regarded as approximation of the original Read code.

An excel file with complete code lists is also available DOI: 10.13140/RG.2.2.14629.42729

Contents:

A1 Supplementary table 1: **Primary care dementia documentation**

Source: adapted from the SAIL Dementia eCohort (Schnier C, Wilkinson T, Orton C, North L, Rochford R, Sudlow C. The Secure Anonymised Information Linkage databank Dementia e-cohort (SAIL-DeC). International Journal of Population Data Science. 2019;4(3).)			
https://static-content.springer.com/esm/art%3A10.1007%2Fs10654-019-00499-1/MediaObjects/10654_2019_499_MOESM1_ESM.pdf			
Description	Read code	SNOMED Concept	"High" or "Low" specificity code
[X] Dementia in Alzheimer's disease	Eu00.	142811000119104	High
[X]Dementia in Alzheimer's disease with early onset	Eu000	416780008	High
[X]Dementia in Alzheimer's disease with late onset	Eu001	416975007	High
[X]Dementia in Alzheimer's disease, atypical or mixed type	Eu002	419261000000107	High
[X]Dementia in Alzheimer's disease, unspecified	Eu00z	26929004	High
Alzheimer’s disease	F110.	26929004	High
Alzheimer’s disease with early onset	F1100	416780008	Low
Alzheimer’s disease with late onset	F1101	416975007	High
Senile degeneration of brain	F112.	45864009	Low
[X] Other Alzheimer's disease	Fyu30	26929004	High
Multi-infarct dementia	E004.	429998004	High

Uncomplicated arteriosclerotic dementia	E0040	191463004	High
Arteriosclerotic dementia with delirium	E0041	191464005	High
Arteriosclerotic dementia with paranoia	E0042	191465006	High
Arteriosclerotic dementia with depression	E0043	191466007	High
Arteriosclerotic dementia NOS	E004z	56267009	High
[X]Vascular dementia	Eu01.	429998004	High
[X]Vascular dementia of acute onset	Eu010	230285003	High
[X]Multi-infarct dementia	Eu011	56267009	High
[X]Other vascular dementia	Eu01y	429998004	High
[X]Vascular dementia, unspecified	Eu01z	429998004	High
Cerebral degeneration due to cerebrovascular disease	F11x2	192813004	Low
Binswanger's disease	F21y2	90099008	High
[X] Lewy body dementia	Eu025	312991009	High
Lewy body disease	F116.	312991009	High
[X] Dementia in Picks disease	Eu020	21921000119103	High
Pick's disease	F111.	13092008	High
Frontotemporal degeneration	F118.	230273006	Low
Jakob-Creutzfeldt disease	A411.	792004	Low
Sporadic Creutzfeldt-Jakob disease	A4110	713060000	Low
Alcoholic dementia, NOS	E012.	281004	Low
Dementia in conditions EC	E041.	191519005	High
[X] Dementia in other diseases classified elsewhere	Eu02.	191519005	High
[X] Dementia in Creutzfeldt-Jacob disease	Eu021	429458009	High
[X] Dementia in Huntington's disease	Eu022	442344002	High
[X] Dementia in Parkinson's disease	Eu023	425390006	High
[X] Dementia in HIV disease	Eu024	421529006	High
[X]Dementia in other specified diseases classified elsewhere	Eu02y	191519005	High
[X]Mental and behavioural disorders due to use of alcohol: amnesic syndrome	Eu106	73097000	Low
[X]Mental and behavioural disorders due to use of alcohol: residual and late-onset psychotic disorder	Eu107	281004	Low
Cerebral degeneration due to Jacob-Creutzfeldt disease	F11x7	192818008	Low
Cerebral degeneration due to Parkinson's disease	F11x9	341551000000108	Low
Corticobasal degeneration	F11y2	18842008	Low

H/O: dementia	1461	161465002	High
Assessment of psychotic and behavioural symptoms of dementia	38C13	700464008	Low
GDS level 4 - moderate cognitive decline	3AE3.	407632003	High
GDS level 5 - moderately severe cognitive decline	3AE4.	407633008	High
GDS level 6 - severe cognitive decline	3AE5.	407634002	High
GDS level 7 - very severe cognitive decline	3AE6.	407635001	High
Dementia monitoring	66h..	248711000000102	High
Dementia annual review	6AB..	249181000000100	Low
Dementia medication review	8BM02	938551000000108	Low
Shared care – prescribing drug for dementia	8BM50	719787003	High
Shared care – prescribing drug for dementia declined	8BM60	720022007	High
Antipsyc drug therapy dementia	8BPa.	700214004	High
Dementia advance care plan	8CMe0	959361000000105	Low
Review of dementia advance care plan	8CMG2	713580008	Low
Dementia care plan	8CMZ.	736371006	Low
Dementia care plan agreed	8CMZ0	956841000000106	Low
Dementia care plan reviewed	8CMZ1	956861000000107	Low
Dementia care plan declined	8CMZ2	956881000000103	Low
Dementia care plan review declined	8CMZ3	956901000000100	Low
Dementia advance care plan agreed	8CSA.	1095121000000100	Low
Referral to dementia care advisor	8Hla.	798381000000109	Low
Dementia adv care plan declnd	8IAe0	956881000000103	Low
Dementia advance care plan review declined	8IAe2	959461000000102	Low
Exception reporting: dementia quality indicators	9hD..	715881000000108	Low
Excepted from dementia quality indicators: patient unsuitable	9hD0.	716341000000104	Low
Excepted from dementia quality indicators: informed dissent	9hD1.	716131000000105	Low
Dementia monitoring administration	9Ou..	713821000000106	Low
Dementia monitoring first letter	9Ou1.	715821000000107	Low
Dementia monitoring second letter	9Ou2.	717471000000101	Low
Dementia monitoring third letter	9Ou3.	716671000000102	Low
Dementia monitoring verbal invite	9Ou4.	716221000000104	Low
Dementia monitoring telephone invite	9Ou5.	716991000000108	Low

Senile and presenile organic psychotic condition	E00..	15662003	Low
Uncomplicated senile dementia	E000.	191449005	High
Pre-senile dementia	E001.	12348006	Low
Uncomplicated pre-senile dementia	E0010	191451009	Low
Pre-senile dementia with delirium	E0011	191452002	Low
Pre-senile dementia with paranoia	E0012	191454001	Low
Pre-senile dementia with depression	E0013	191455000	Low
Pre-senile dementia NOS	E001z	12348006	Low
Senile dementia with depressive or paranoid features	E002.	191457008	High
Senile dementia with paranoia	E0020	191458003	High
Senile dementia with depression	E0021	191459006	High
Senile dementia with depressive or paranoid features NOS	E002z	191457008	High
Senile dementia with delirium	E003.	191461002	Low
Drug induced dementia	E02y1	191493005	Low
[X]Sub-cortical vascular dementia	Eu012	230286002	High
[X]Mixed cortical and sub-cortical vascular dementia	Eu013	230287006	High
[X] Unspecified dementia	Eu02z	22381000119105	High
[X] Delirium superimposed on dementia	Eu041	2776000	Low

A1 Supplementary table 2: **Primary care documentation of dementia subtypes (all occur in above dementia documentation). Key: AD = Alzheimer's-type dementia, VD = Vascular dementia, O = Dementia of other type**

Source: https://static-content.springer.com/esm/art%3A10.1007%2Fs10654-019-00499-1/MediaObjects/10654_2019_499_MOESM1_ESM.pdf

Description	Read code	SNOMED Concept	Subtype
[X] Dementia in Alzheimer's disease	Eu00.	142811000119104	AD
[X]Dementia in Alzheimer's disease with early onset	Eu000	416780008	AD
[X]Dementia in Alzheimer's disease with late onset	Eu001	416975007	AD
[X]Dementia in Alzheimer's disease, atypical or mixed type	Eu002	419261000000107	AD
[X]Dementia in Alzheimer's disease, unspecified	Eu00z	26929004	AD
Alzheimer's disease	F110.	26929004	AD
Alzheimer's disease with early onset	F1100	416780008	AD
Alzheimer's disease with late onset	F1101	416975007	AD
Senile degeneration of brain	F112.	45864009	AD
[X] Other Alzheimer's disease	Fyu30	26929004	AD
Multi-infarct dementia	E004.	429998004	VD
Uncomplicated arteriosclerotic dementia	E0040	191463004	VD
Arteriosclerotic dementia with delirium	E0041	191464005	VD
Arteriosclerotic dementia with paranoia	E0042	191465006	VD
Arteriosclerotic dementia with depression	E0043	191466007	VD
Arteriosclerotic dementia NOS	E004z	56267009	VD
[X]Vascular dementia	Eu01.	429998004	VD
[X]Vascular dementia of acute onset	Eu010	230285003	VD
[X]Multi-infarct dementia	Eu011	56267009	VD
[X]Other vascular dementia	Eu01y	429998004	VD
[X]Vascular dementia, unspecified	Eu01z	429998004	VD
Cerebral degeneration due to cerebrovascular disease	F11x2	192813004	VD
Binswanger's disease	F21y2	90099008	VD
[X] Lewy body dementia	Eu025	312991009	O
Lewy body disease	F116.	312991009	O
[X] Dementia in Picks disease	Eu020	21921000119103	O
Pick's disease	F111.	13092008	O
Frontotemporal degeneration	F118.	230273006	O
Alcoholic dementia, NOS	E012.	281004	O
[X]Mental and behavioural disorders due to use of alcohol: amnesic syndrome	Eu106	73097000	O
[X]Mental and behavioural disorders due to use of alcohol: residual and late-onset psychotic disorder	Eu107	281004	O

A1 Supplementary table 3: **Consultation types in Lambeth DataNet**

Source: Generated internally		
ConsultationTypeTerm	**N_total in LDN**	**included**
GP Surgery	30047521	Y
Externally entered note	11897955	N
Administration note	8104352	N
Scanned document	7297117	N
Patient encounter data NOS	5699995	N
Telephone consultation	3227510	Y
Laboratory result	2357993	N
NULL	1958780	N
Face to face consultation	613991	Y
Mail from patient	402619	N
Other note	389818	N
Hospital outpatient report	341925	N
Home visit note	259265	Y
Non-consultation data	248453	N
Telephone call to a patient	243062	Y
Non-consultation medication data	212227	N
Telephone encounter	209876	Y
Did not attend	186524	N
Inbound document	156727	N
Walk-in clinic	143437	Y
Telephone triage encounter	138996	Y
Urgent consultation	112410	Y
Emergency consultation	112370	Y
Night visit note	98111	Y
Indirect encounter	90961	N
Repeat prescription	90489	N
SMS text message sent to patient	65309	N
OOH report	47896	N
Discussion with colleague	37663	N
Extended hours consultation	23731	Y
Telephone call to relative/carer	20565	N
Mail to patient	20152	N
E-mail consultation	19515	N
Hospital inpatient report	18553	N
Seen in baby clinic	11996	N
Telephone call from relative/carer	8936	N
Residential home visit note	**8544**	**Y**
Online communication	8102	N
Other consultation medium used	7328	Y
E-mail received from patient	6086	N

Group consultation	4643	N
E-mail sent to patient	4326	N
Seen in private clinic	3208	N
Case conference	2839	N
Emergency appointment	2763	Y
Seen in asthma clinic	1589	Y
School visit note	1583	N
Multidisciplinary team meeting with patient	1200	Y
Discussion with other professional	1036	N
Face to face consultation with relative/carer	805	N
Same day appointment	699	Y
Children's home visit note	688	N
Enterprise consultation	533	N
Hospital inpatient note	516	N
Consultation via telemedicine web camera	514	N
Consultation via multimedia	292	N
Routine consultation	269	Y
Seen in GP unit	251	Y
Radiology result	241	N
Pharmacy consultation	175	N
Nurse telephone triage	134	N
Multidisciplinary team meeting without patient	116	N
First attendance face to face	100	Y
Follow up attendance face to face	95	Y
Genito-urinary medicine	87	N
Medication requested	34	N
Inbound referral	30	N
E-mail received from carer	27	N
Outbound referral	21	N

A1 Supplementary table 4: **Smoking status documentation**

Key: 1 = current smoker strong code, 2 = current smoker weak code, 3 = Ever smoker, 4 = Not current, 5 = Never smoked

Algorithm used: *Sum up number in each category. If category (1) has the most and there are no (5), then **current smoker**. If category (5) has the most and there are no (1) then **never smoker**. All other are **mixed/former** smoker*.

Collated by Katrina Davis (katrina.davis@kcl.ac.uk) and Catherine Polling

Description	Read code	SNOMEDConcept NA = no match	Smoking status
Smoking cessation advice	8CAL.	225323000	1
Cigarette smoker	137P.	65568007	1
Current smoker	137R.	77176002	1
Moderate smoker - 10-19 cigs/d	1374.	160604004	1
Light smoker - 1-9 cigs/day	1373.	160603005	1
Heavy smoker - 20-39 cigs/day	1375.	160605003	1
Trivial smoker - < 1 cig/day	1372.	428041000124106	1
Rolls own cigarettes	137M.	160619003	1
Smoking cessation advice declined	8IAj.	527151000000107	1
Referral to smoking cessation advisor	8H7i.	395700008	1
Cigar smoker	137J.	59978006	1
Pipe smoker	137H.	82302008	1
Not interested in stopping smoking	137d.	394873005	1
Lifestyle advice regarding smoking	67H1.	225323000	1
Smoking cessation drug therapy declined	8IEM.	822591000000108	1
Thinking about stopping smoking	137c.	394871007	1
Smoking cessation programme declined	8IEK.	1087441000000100	1
Very heavy smoker - 40+cigs/d	1376.	160606002	1
Failed attempt to stop smoking	137m.	446172000	1
Keeps trying to stop smoking	137C.	160612007	1
Stop smoking service opportunity signposted	8CdB.	783011000000105	1
Tobacco dependence	E251.	89765005	1
Smoking reduced	137V.	134406006	1
Current smoker annual review - enhanced services administration	9ko..	505651000000103	1
Smoking restarted	137e.	308438006	1
[V]Tobacco use	ZV4K0	110483000	1
Smoking cessation advice provided by community pharmacist	8CAg.	200221000000105	1
Minutes from waking to first tobacco consumption	137h.	413173009	1
Reason for restarting smoking	137f.	401159003	1
[X]Mental and behavioural disorders due to use of tobacco: harmful use	Eu171	470041000000100	1

[V]Tobacco abuse counselling	ZV6D8	711028002	1
[X]Mental and behavioural disorders due to use of tobacco: acute intoxication	Eu170	466951000000105	1
Tobacco dependence, continuous	E2511	191887008	1
[X]Mental and behavioural disorder due to use of tobacco	Eu17.	30310000	1
Varenicline smoking cessation therapy declined	8IEM0	966971000000103	1
Tobacco consumption	137..	266918002	2
Tobacco consumption NOS	137Z.	266918002	2
Stop smoking monitor 1st lettr	9OO4.	185792005	2
Cigarette consumption	137X.	230056004	2
Smoking started	137Q.	266929003	2
Pipe tobacco consumption	137a.	230058003	2
Stop smoking monitor 2nd lettr	9OO5.	185793000	2
Stop smoking monitor verb.inv.	9OO7.	185795007	2
Cigar consumption	137Y.	230057008	2
Attends stop smoking monitor.	9OO1.	185789006	2
Refuses stop smoking monitor	9OO2.	765001003	2
Smokers' cough	H3101	46802002	2
Stop smoking monitor 3rd lettr	9OO6.	185794006	2
Stop smoking monitor phone inv	9OO8.	185796008	2
Stop smoking monitor.chck done	9OOA.	185799001	2
Waterpipe tobacco consumption	137o.	836001000000109	2
Stop smoking invitation first short message service text message	9OOB0	783401000000101	2
Chronic obstructive pulmonary disease structured smoking assessment declined - enhanced services administration	9kf2.	375911000000102	2
Stop smoking invitation third short message service text message	9OOB2	783481000000106	2
Fagerstrom test for nicotine dependence	38DH.	1084701000000100	2
Toxic effect of tobacco and nicotine	SMC..	212899006	2
Stop smoking invitation second short message service text message	9OOB1	783441000000103	2
Stop smoking invitation short message service text message	9OOB.	783381000000101	2
Tobacco dependence NOS	E251z	89765005	2
[X]Mental and behavioural disorders due to use of tobacco: other mental and behavioural disorders	Eu17y	396621000000103	2
[X]Mental and behavioural disorders due to use of tobacco: unspecified mental and behavioural disorder	Eu17z	466861000000102	2
Tobacco dependence, episodic	E2512	191888003	2
Ex smoker	137S.	8517006	3
Stopped smoking	137K.	160617001	3

Ex-moderate smoker (10-19/day)	1379.	266923002	3
Ex-smoker - amount unknown	137F.	266928006	3
Ex-light smoker (1-9/day)	1378.	266922007	3
Ex-heavy smoker (20-39/day)	137A.	266924008	3
Trying to give up smoking	137G.	160616005	3
Date ceased smoking	137T.	160625004	3
Ex-cigarette smoker	137j.	281018007	3
Ex-trivial smoker (<1/day)	1377.	266921000	3
Ex-very heavy smoker (40+/day)	137B.	266925009	3
Nicotine replacement therapy	8B2B.	313396002	3
Referral to stop-smoking clinic	8HTK.	315232003	3
Smoking cessation therapy	745H.	710081004	3
Total time smoked	137n.	228487000	3
Referral to NHS stop smoking service	8HkQ.	505281000000106	3
Ready to stop smoking	137b.	203191000000107	3
Cigarette pack-years	137g.	401201003	3
Ex pipe smoker	137N.	160620009	3
Smoking cessation milestones	13p..	390900001	3
Seen by smoking cessation advisor	9N2k.	401068004	3
Brief intervention for smoking cessation	67H6.	506491000000102	3
Referral to smoking cessation service declined	8IEo.	871641000000105	3
Referral for smoking cessation service offered	9NS02	767641000000109	3
Ex cigar smoker	137O.	160621008	3
Nicotine replacement therapy provided free	8B3f.	390905006	3
Declined consent for follow-up by smoking cessation team	9Ndg.	755741000000100	3
Nicotine replacement therapy using nicotine patches	745H0	790121000000107	3
Negotiated date for cessation of smoking	13p0.	390901002	3
Recently stopped smoking	137K0	517211000000106	3
Smoking cessation drug therapy	745H4	713700008	3
Over the counter nicotine replacement therapy	8B3Y.	315055008	3
DNA - Did not attend smoking cessation clinic	9N4M.	25261000000107	3
Ex roll-up cigarette smoker	137l.	492191000000103	3
Smoking cessation programme start date	13p5.	401160008	3
Smoking cessation therapy NOS	745Hz	NA	3
Referral to smoking cessation service	8T08.	871661000000106	3
Nicotine replacement therapy refused	8I39.	315022003	3
Smoking free weeks	13p4.	395177003	3
Nicotine replacement therapy using nicotine inhalator	745H2	280811000000104	3
Ex-smoker annual review - enhanced services administration	9km..	505761000000105	3
Other specified smoking cessation therapy	745Hy	NA	3
Smoking status at 4 weeks	13p1.	390902009	3

Stop smoking face to face follow-up	8HBM.	505581000000108	3
Practice based smoking cessation programme start date	13p50	712971000000108	3
Ex-smoker	137s.	NA	3
Consent given for follow-up by smoking cessation team	9Ndf.	755721000000107	3
Nicotine replacement therapy using nicotine gum	745H1	280801000000101	3
Carbon monoxide reading at 4 weeks	13p6.	413753009	3
Smoking status between 4 and 52 weeks	13p2.	390903004	3
Nicotine replacement therapy using nicotine lozenges	745H3	790131000000109	3
Nicotine withdrawal	E023.	90755006	3
Smoking cessation - enhanced services administration	9kc..	374361000000100	3
Declined consent for smoking cessation data sharing	9NdZ.	751661000000106	3
Consent given for smoking cessation data sharing	9NdW.	750851000000104	3
Declined consent for follow-up evaluation after smoking cessation intervention	9NdY.	751101000000101	3
Smoking status at 12 weeks	13p7.	766931000000106	3
Smoking status at 52 weeks	13p3.	390904005	3
Lost to smoking cessation follow-up	13p8.	768971000000109	3
Smoking cessation 12 week follow-up	8HBP.	850331000000104	3
Nicotine replacement therapy provided by community pharmacist	8BP3.	200211000000104	3
Varenicline therapy	745H5	719591006	3
Consent given for follow-up evaluation after smoking cessation intervention	9NdV.	750821000000109	3
Referred for chronic obstructive pulmonary disease structured smoking assessment - enhanced services administration	9kf1.	375851000000108	3
Varenicline smoking cessation therapy offered	8B31G	966991000000104	3
Nicotine replacement therapy contraindicated	8I2I.	395174005	3
Smoking cessation monitoring template completed - enhanced services administration	9kc0.	374391000000106	3
[X]Mental and behavioural disorders due to use of tobacco: withdrawal state	Eu173	411461000000105	3
Issue of nicotine replacement therapy voucher	8B2B0	784481000000108	3
Current non-smoker	137L.	160618006	4
Non-smoker annual review - enhanced services administration	9kn..	505681000000109	4
Never smoked tobacco	XE0oh	266919005	5
Non-smoker (& [never smoked tobacco])	1371.	266919005	5

A1 Supplementary table 5: **Charlson comorbidity index overview**

Full lists can be seen DOI: 10.13140/RG.2.2.14629.42729. Weights as per: Quan H, Li B, Couris CM, Fushimi K, Graham P, Hider P, et al. Updating and Validating the Charlson Comorbidity Index and Score for Risk Adjustment in Hospital Discharge Abstracts Using Data From 6 Countries. American Journal of Epidemiology. 2011;173(6):676-82.
https://academic.oup.com/aje/article/173/6/676/182985

Collated by Katrina Davis (katrina.davis@kcl.ac.uk) and Ruimin Ma
Based on codes in CALIBER (https://www.caliberresearch.org/portal/show/charlson_composite)

		Weights		
Item	Notes	Original	Modified	This study
Myocardial infarct	Unchanged from CALIBER	1	0	0
Heart failure	Unchanged from CALIBER	1	2	2
Peripheral aterial	We noted that the code list did not include procedures relating to abdominal aortic aneurysms, but did not change this	1	0	0
Stroke	Unchanged from CALIBER	1	0	0
Dementia	Not included	1	2	0
Asthma and COPD	Unchanged from CALIBER	1	1	1
Connective tissue	Unchanged from CALIBER	1	1	1
Peptic ulcer	CALIBER included only gastric disorders, which we widened to include duodenal ulcers and peptic ulcers without position stated	1	0	0
Liver	We combined the list for mild and severe illness, as it was felt there was insufficient specificity between the lists	1 (3)	2 (4)	2
Diabetes	Unchanged from CALIBER	1	0	0
Paralysis	CALIBER included only hemiplegia, whereas paraplegia is also intended for the charlson, so added	2	2	2
Renal failure	Unchanged from CALIBER	2	1	1
Complications of diabetes	Unchanged from CALIBER	2	1	1
Cancer in last 5 years	We removed the group of codes relating to “history of” cancer given the timing of this item is important	2	2	2
HIV	The original item was AIDS, but we have kept the shift in the existing codes to diagnosis of HIV, aware that this is likely to reduce the weighting of this item when we calculate this	6	4	4
Cancer with metastases	Unchanged from CALIBER	6	6	6

A1 Supplementary table 6: **Dementia medication**

Sub-class	Medication name / Trade name
Donepezil	Donepezil
	Aricept Evess
	Aricept
Memantine	Memantine
	Alzhok
	Ebixa
	Nemdatine
	Marixino
	Valios
Other	Galantamine
	Galzemic
	Reminyl
	Acumor XL
	Consion XL
	Elmino XL
	Gaalin
	Galsya XL
	Galzemic XL
	Gatalin XL
	Gazylan XL
	Lotprosin XL
	Luventa XL
	Reminyl XL
	Rivastigmine
	Nimvastid
	Almuriva
	Alzest
	Exelon
	Voleze
	Erastig

Appendix 2: [table] Proportion of people with dementia identified by two sources looking over time and by Lambeth residence

Table A2

			Documentation of dementia diagnosis				
Documentation of dementia	total	n. diagnoses per year	Both primary care and specialist	Primary care only	Specialist only	Primary care code (+/- specialist)	In specialist database (+/- primary care)
Date of first documentation			Cohort with Lambeth GP			Cohort with Lambeth GP	
2007-2010	1578	*395*	828 (52%)	246 (16%)	504 (32%)	1074 (68%)	1332 (73%)
2011-2015	2316	*463*	1290 (56%)	489 (21%)	537 (23%)	1779 (77%)	1827 (65%)
2016-2019	1345	*336*	768 (57%)	238 (18%)	339 (25%)	1006 (75%)	1107 (70%)
total	**5239**		**2886 (55%)**	**973 (19%)**	**1380 (26%)**	**3859 (74%)**	**4266 (69%)**
Date of first documentation			Cohort with Lambeth GP and address			Cohort Lambeth GP and address	
2007-2010	1317	*329*	713 (54%)	212 (16%)	392 (30%)	925 (70%)	1105 (72%)
2011-2015	1947	*463*	1123 (58%)	414 (21%)	410 (21%)	1537 (79%)	1533 (65%)
2016-2019	1126	*282*	662 (59%)	200 (18%)	264 (23%)	862 (77%)	926 (70%)
total	**4390**		**2498 (57%)**	**826 (19%)**	**1066 (24%)**	**3324 (76%)**	**3564 (68%)**

Appendix 3: [table] Characteristics and missing data for main cohort from Lambeth DataNet, compared against those also with Lambeth residence.

Table A3 Cohort characteristics – LDN patients with dementia documentation in primary care and/or specialist sources

	Main cohort (regardless of residence) n=5239	Lambeth resident n=4390
Age group		
65-74	1006 (19%)	847 (19%)
75-84	2379 (45%)	2012 (46%)
85+	1854 (35%)	1531 (35%)
Sex		
F	3131 (60%)	2593 (59%)
M	2108 (40%)	1797 (41%)
Ethnicity		
British	2057 (39%)	1683 (38%)
Black	1182 (23%)	1078 (25%)
White	785 (15%)	674 (15%)
Asian	281 (5%)	239 (5%)
mixed	134 (3%)	120 (3%)
other	56 (1%)	47 (1%)
missing	744 (14%)	549 (13%)
IMD		
Mid-Low deprivation	3052 (58%)	2524 (57%)
High deprivation	2076 (40%)	1866 (43%)
missing	111 (2%)	NA
Smoking status		
never	1750 (33%)	1495 (34%)
missing	651 (12%)	462 (11%)
Comorbidity index		
0	1879 (36%)	1509 (34%)
1	1084 (21%)	901 (21%)
2 to 3	1654 (32%)	1433 (33%)
4 to 5	500 (10%)	439 (10%)
6+	122 (2%)	108 (2%)
Consultation rate		
Above-average	2673 (51%)	2303 (52%)
Below average	1767 (34%)	1490 (34%)
None	799 (15%)	597 (14%)
Care home		
Yes	380 (7%)	373 (8%)
No	4859 (93%)	4017 (92%)
Death		
During follow-up	1373 (26%)	1214 (28%)
Not during follow-up	3866 (74%)	3176 (72%)
Dementia type		
Alzheimer's/Mixed	2863 (55%)	2359 (54%)
Vascular	1142 (22%)	984 (22%)
Other	215 (4%)	186 (4%)
missing / unsp	1019 (19%)	861 (20%)

CRIS record (contact with specialist mental health services)		
Yes	4621 (88%)	3856 (88%)
No	618 (12%)	534 (12%)
Total	**5239**	**4390**

Appendix 4: [table] Characteristics of patients with dementia documented in either specialist database or primary care database or both

Table A4 (A-C) Characteristics of patients with dementia documented in either specialist database or primary care database or both. A. Excludes missing data, with proportions indicating the proportion of documented cases (as per Table 1 and 2) B. Accounts for missing data in proportions C. Accounts for missing and restricts to those with prior consultation.

A. Variable n				
Proportion with 95% confidence intervals. Variable n due to exclusion of values that are missing.				
		Both sources	Specialist only	Primary care only
Age group (n=5239)		n.2880	n.1380	n.973
	65-74	18% (17-20)	19% (17-22)	22% (19-24)
	75-84	47% (45-49)	43% (40-45)	44% (41-47)
	85+	34% (33-36)	38% (35-40)	35% (32-38)
Sex (n=5239)		n.2880	n.1380	n.973
	Female	61% (59-63)	57% (55-60)	59% (56-62)
	Male	39% (37-41)	43% (40-45)	41% (38-44)
Ethnicity (n=4495)		n.2662	n.925	n.908
	British	44% (42-46)	51% (48-54)^	45% (42-48)
	Black	27% (26-29)	22% (19-25)*	28% (25-31)
	White non-British	18% (17-20)	17% (14-19)	15% (13-18)

B. Full cohort				
Proportion and 95% confidence interval. N = 5239 throughout				
		Both (n.2886)	Specialist (n.1380)	Primary care (n.973)
Age group (n=5239)				
	65-74	18% (17-20)	19% (17-22)	22% (19-24)
	75-84	47% (45-49)	43% (40-45)	44% (41-47)
	85+	34% (33-36)	38% (35-40)	35% (32-38)
Sex (n=5239)				
	Female	61% (59-63)	57% (55-60)	59% (56-62)
	Male	39% (37-41)	43% (40-45)	41% (38-44)
Ethnicity (n=5239)				
	British	41% (39-43)	34% (32-37)*	42% (39-45)
	Black	25% (24-27)	15% (13-17)*	26% (23-29)
	White non-British	17% (16-18)	11% (10-13)*	14% (12-17)*

C. Restricting to patients with prior consultation				
Proportion and 95% confidence interval. N = 4440 throughout				
		Both (n.2660)	Specialist (n.900)	Primary care (n.880)
Age group (n=4440)				
	65-74	18% (16-19)	18% (15-20)	22% (19-24)
	75-84	47% (46-49)	41% (38-44)*	44% (40-47)
	85+	35% (33-37)	41% (38-44)^	35% (32-38)
Sex (n=4440)				
	Female	61% (59-63)	57% (54-60)	59% (56-63)
	Male	39% (37-41)	43% (40-46)	41% (37-44)
Ethnicity (n=4440)				
	British	41% (39-43)	44% (41-47)	41% (38-44)
	Black	26% (25-28)	18% (15-20)*	27% (25-30)
	White non-British	17% (16-19)	14% (12-16)	14% (12-17)

A. Variable n			
Asian	5.7% (4.9-6.6)	7.0% (5.6-8.9)	7.2% (5.7-9)
Mixed	3.0% (2.5-3.8)	2.8% (1.9-4.1)	3% (2.1-4.3)
Other	1.2% (0.8-1.6)	0.6% (0.3-1.4)	2.1% (1.3-3.2)
Missing	omitted	omitted	omitted
Deprivation (IMD) (n=5128)	n.2829	n.1345	n.954
Quintile 2-5	59% (57-61)	60% (57-63)	60% (57-63)
Quintile 1 (most deprived)	41% (39-43)	40% (37-43)	40% (37-43)
Missing address	omitted	omitted	omitted
Smoking (n=4589)	n.2770	n.878	n.941
Never	37% (35-38)	43% (40-46)^	37% (34-40)
Former / mixed	48% (46-50)	37% (34-40)*	46% (43-49)
Current	15% (14-17)	20% (17-22)	18% (15-20)
Missing	omitted	omitted	omitted
Primary care consultations (n=5239) (a)			
Above average	59% (57-60)	36% (34-39)*	50% (47-53)*
Average or less	34% (32-35)	29% (27-31)*	41% (38-44)^
None	8% (7-9)	35% (32-37)^	10% (8-12)
Care home residence (n=5239) (a)			

B. Full cohort			
Asian	5% (4-6)	5% (4-6)	7% (5-8)
Mixed	3% (2-3)	2% (1-3)	3% (2-4)
Other	1% (1-2)	0% (0-1)	2% (1-3)
Missing	8% (7-9)	33% (31-35)^	7% (5-8)
Deprivation (IMD) (n=5239)			
Quintile 2-5	58% (56-60)	58% (56-61)	59% (56-62)
Quintile 1 (most deprived)	40% (38-42)	39% (37-42)	39% (36-42)
Missing address	2% (2-3)	3% (2-4)	2% (1-3)
Smoking (n=5239)			
Never	35% (33-37)	27% (25-30)*	35% (32-38)
Former / mixed	46% (44-48)	24% (21-26)*	44% (41-47)
Current	15% (14-16)	13% (11-14)	17% (15-20)
Missing	4% (3-5)	36% (34-39)^	3% (2-5)
Primary care consultations (n=5239) (a)			
Above average	59% (57-60)	36% (34-39)*	50% (47-53)*
Average or less	34% (32-35)	29% (27-31)*	41% (38-44)^
None	8% (7-9)	35% (32-37)^	10% (8-12)
Care home residence (n=5239) (a)			

C. Restricting to patients with prior consultation			
Asian	5% (4-6)	5% (4-7)	7% (5-9)
Mixed	3% (2-4)	2% (2-4)	3% (2-4)
Other	1% (1-2)	0% (0-1)	2% (1-3)
Missing	6% (5-7)	17% (14-19)^	6% (5-8)
Deprivation (IMD) (n=4440)			
Quintile 2-5	59% (57-61)	59% (56-62)	59% (56-62)
Quintile 1 (most deprived)	39% (37-41)	39% (36-42)	39% (36-42)
Missing address	2% (2-3)	2% (1-3)	2% (1-3)
Smoking (n=4440)			
Never	34% (33-36)	34% (31-37)	34% (31-37)
Former / mixed	47% (45-49)	33% (30-36)*	45% (42-48)
Current	16% (14-17)	17% (15-20)	18% (16-21)
Missing	3% (3-4)	16% (14-19)^	3% (2-4)
Primary care consultations (n=4440) (a)			
Above average	63% (62-65)	56% (52-59)*	55% (52-58)*
Average or less	37% (35-38)	44% (41-48)^	45% (42-48)^
None			omitted
Care home residence (n=4440) (a)			

A. Variable n				
	Yes	8% (7-9)	3% (3-4)*	11% (9-13)
	No	92% (91-93)	97% (96-97)^	89% (87-91)
Comorbidity index (n=5239)(a)(c)				
	0	31% (30-33)	47% (45-50)^	33% (30-36)
	1	22% (20-23)	20% (18-22)	19% (17-22)
	2 to 3	34% (33-36)	24% (22-27)*	34% (31-37)
	4 to 5	10% (9-12)	7% (6-8)*	11% (9-13)
	6+	2.3% (1.8-2.9)	1.7% (1.2-2.6)	3.4% (2.4-4.7)
Mortality(n=5239)(b)				
	No	76% (75-78)	72% (70-75)	69% (66-72)*
	Yes	24% (22-25)	28% (25-30)	31% (28-34)^
Subtype (n=4220)		n.2644	n.1026	n.550
	Alzheimers / mixed	74% (73-76)	60% (57-63)*	52% (48-56)*
	Vascular	21% (20-23)	34% (31-37)^	41% (37-45)^
	Other specified	4.3% (3.6-5.2)	6% (4.7-7.7)	7.1% (5.2-9.5)
	Unspecified	omitted	omitted	omitted
Dementia medication(n=5239)(b)				
	No	59% (57-61)	92% (91-94)^	77% (74-80)^
	Yes	41%	8%	23%

B. Full cohort				
	Yes	8% (7-9)	3% (3-4)*	11% (9-13)
	No	92% (91-93)	97% (96-97)^	89% (87-91)
Charlson comorbidity index(n=5239)(a)(c)				
	0	31% (30-33)	47% (45-50)^	33% (30-36)
	1	22% (20-23)	20% (18-22)	19% (17-22)
	2 to 3	34% (33-36)	24% (22-27)*	34% (31-37)
	4 to 5	10% (9-12)	7% (6-8)*	11% (9-13)
	6+	2.3% (1.8-2.9)	1.7% (1.2-2.6)	3.4% (2.4-4.7)
Mortality(n=5239)(b)				
	Alive	76% (75-78)	72% (70-75)	69% (66-72)*
	Death within 4y	24% (22-25)	28% (25-30)	31% (28-34)^
Subtype (n=5239)				
	Alzheimers / mixed	68% (66-70)	44% (42-47)*	29% (27-32)*
	Vascular	20% (18-21)	25% (23-28)^	23% (21-26)^
	Other specified	4% (3-5)	4% (4-6)	4% (3-5)
	Unspecified	8% (7-9)	26% (23-28)^	43% (40-47)^
Dementia medication(n=5239)(b)				
	No	59% (57-61)	92% (91-94)^	77% (74-80)^
	Yes	41%	8%	23%

C. Restricting to patients with prior consultation				
	Yes	7% (6-8)	4% (3-6)	11% (9-13)^
	No	93% (92-94)	96% (94-97)	89% (87-91)*
Charlson comorbidity index(n=4440)(a)(c)				
	0	28% (27-30)	34% (31-37)^	30% (28-34)
	1	22% (20-23)	23% (21-26)	19% (17-22)
	2 to 3	36% (34-38)	31% (28-34)	35% (32-38)
	4 to 5	11% (10-13)	10% (8-12)	12% (10-14)
	6+	2% (2-3)	2% (2-4)	4% (3-5)
Mortality(n=4440)(b)				
	Alive	76% (75-78)	63% (60-66)*	68% (65-71)*
	Death within 4y	24% (22-25)	37% (34-40)^	32% (29-35)^
Subtype (n=4220)				
	Alzheimers / mixed	69% (67-71)	38% (34-41)*	29% (26-32)*
	Vascular	19% (18-20)	27% (24-30)^	21% (19-24)
	Other specified	4% (3-5)	5% (4-7)	4% (3-5)
	Unspecified	8% (7-9)	30% (28-34)^	46% (43-49)^
Dementia medication(n=4440)(b)				
	No	58% (56-60)	89% (87-91)^	77% (74-79)^
	Yes	42%	11%	23%

A. Variable n				
		(39-43)	(6-9)*	(20-26)*

B. Full cohort				
		(39-43)	(6-9)*	(20-26)*

C. Restricting to patients with prior consultation				
		(40-44)	(9-13)*	(21-26)*

a) As documented before the first dementia documentation

b) In the four years post-first dementia documentation, or august 2019 if earlier

c) Modified Charlson comorbidity index from primary care-coded morbidities and weights in Quan et al.

^ 95% confidence intervals suggest above proportion for those in both databases (not formally tested, no correction for multiple comparisons)

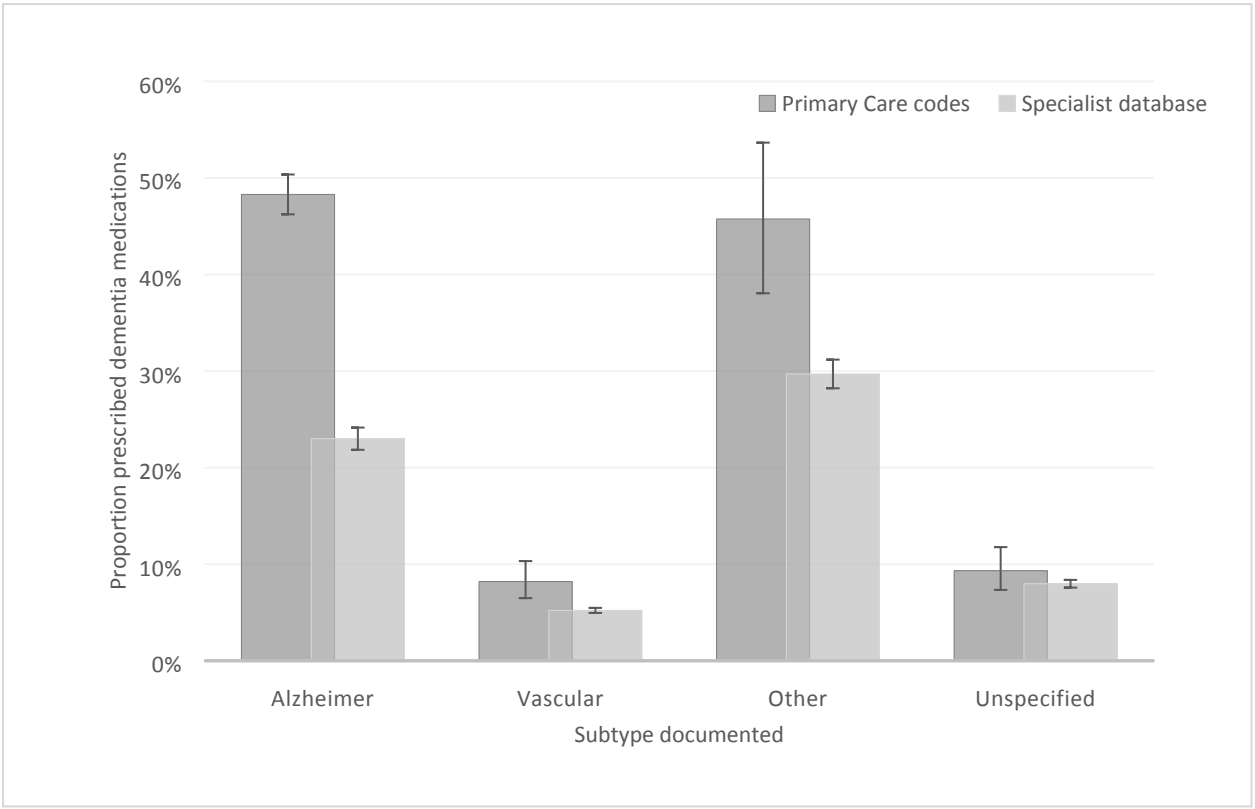
* 95% confidence intervals suggest below proportion for those in both databases (not formally tested, no correction for multiple comparisons)

Appendix 5: [table&figure] Prescription of dementia medication in primary care by source of dementia documentation and subtype of dementia

Table A5: Proportion of patients prescribed dementia medication grouped by documentation source and subtype of dementia (bars are 95% confidence intervals)

	n. prescribed dementia medications / N. patients in category, proportion prescribed dementia medication (95% confidence intervals)			
	source of dementia identification			
Subtype	both specialist and primary care	specialist database only	primary care codes only	**Overall**
Alzheimers / Mixed	1022 / 1963	64 / 614	143 / 286	**1229 / 2863**
	52% (50-54)	10% (8-13)	50% (44-56)	**43% (41-45)**
Vascular	53 / 567	12 / 350	12 / 350	**83 / 1142**
	9% (7-12)	3% (2-6)	8% (5-12)	**7% (6-9)**
Other specified	53 / 567	12 / 62	18 / 39	**88 / 215**
	51% (42-60)	19% (11-31)	46% (32-61)	**41% (35-48)**
Unspecified or missing	58 / 114	19 / 354	43 / 423	**105 / 1019**
	18% (13-23)	5% (3-8)	10% (8-13)	**10% (9-12)**
Overall	**1176 / 2886**	**107 / 1380**	**222 / 973**	**1505 / 5239**
	41% (39-43)	**8% (6-9)**	**23% (20-26)**	**29% (28-30)**

Figure A5: Proportion of patients prescribed dementia medication grouped by documentation source and subtype of dementia (bars are 95% confidence intervals)


60%
50%
40%
30%
20%
10%
0%
Proportion prescribed dementia medications
Primary Care codes
Specialist database
Alzheimer
Vascular
Other
Unspecified
Subtype documented