Primary Health Care Research & Development 2017; **18:** 235–241
doi:10.1017/S146342361700007X

RESEARCH

Variations in dementia diagnosis in England and association with general practice characteristics

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Objectives: Improving dementia diagnosis rates in England has been a key strategic aim of the UK Government but the variation and low diagnosis rates are poorly understood. The aim of this study was to explore the variation in actual versus expected diagnosis of dementia across England, and how these variations were associated with general practice characteristics. **Method:** A cross-sectional, ecological study design using secondary data sources and median regression modelling was used. Data from the year 2011 for 7711 of the GP practices in England (92.7%). Associations of dementia diagnosis rates (%) per practice, calculated using National Health Service England's 'Dementia Prevalence Calculator' and various practice characteristics were explored using a regression model. **Results:** The median dementia diagnosis rate was 41.6% and the interquartile range was 31.2–53.9%. Multivariable regression analysis demonstrated positive associations between dementia diagnosis rates and deprivation of the population, overall Quality and Outcomes Framework performance, type of primary care contract and size of practice list. Negative associations were found between dementia diagnosis rates and average experience of GPs in the practice and the proportion of the practice caseload over 65 years old. **Conclusion:** Dementia diagnosis rates vary greatly across GP practices in England. This study has found independent associations between dementia diagnosis rates and a number of patient and practice characteristics. Consideration of these factors locally may provide targets for case-finding interventions and so facilitate timely diagnosis.

Key words: dementia; diagnosis; health-care quality; mental disorders; population characteristics

Received 3 December 2015; revised 16 January 2017; accepted 18 January 2017; first published online 6 March 2017

Introduction

Current National Health Service (NHS) policy promotes the potential benefits of early identification of dementia and the appropriate treatment and support to those who experience this condition (Department of Health, 2009). However, in 2012, NHS England estimated that only 47% of people with dementia had been diagnosed (Department of Health, 2012a). NHS England has been aiming to improve the diagnosis rates for dementia, following the Prime Minister's Challenge to achieve two thirds of people with dementia being diagnosed by April 2015 (Department of Health, 2012b). 'Diagnosis rate' has been used as a term by the UK Government to describe the proportion of people predicted

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to have dementia in the population, who actually have a recorded diagnosis on electronic medical records in primary care.

Diagnosing dementia in primary care is not straightforward and requires the recognition of a syndrome which is challenging (Wilcock *et al*., 2015). Large variation in the diagnosis rates has been reported, with some known factors associated with dementia diagnosis. Estimates of diagnosis rates indicated they ranged from 39 to 75% across areas of England in 2012 (Department of Health, 2013). One previous study (Connolly *et al*., 2011) explored dementia diagnosis rates in Greater Manchester, England. The study found that singlehanded practices and practices in more affluent areas had significantly lower rates of dementia diagnosis.

Variation in diagnosis rates has been more extensively explored for other diseases, such as coronary heart disease, cancer and hepatitis. Several characteristics of general practices have been found to be associated with variations in diagnosis including deprivation of the practice population (Saxena *et al*., 2007; Bottle *et al*., 2012), singlehanded practices (Coupland *et al*., 2006), practice size (Saxena *et al*., 2007), size of caseload (Saxena *et al*., 2007), patient access (Bottle *et al*., 2012), doctor characteristics (Coupland *et al*., 2006; Bottle *et al*., 2012), Quality and Outcomes Framework (QOF) performance (Bottle *et al*., 2012) and financial factors related to GP contracts (Morgan and Beerstecher, 2006). However, similar associations with dementia diagnosis have not previously been explored in the same way, other than the Greater Manchester study. We chose variables within our study based on these findings from studies in other diseases.

Using publically available data from across England we explored the association between dementia diagnosis rates of GP practices with a range of patient and practice characteristics to identify possible targets for intervention.

Methods

Study design and sample

We used a cross-sectional, ecological study design that sourced publicly available data from various sources for the year 2011 across all GP practices in England. Our outcome was the reported number of patients with a recorded dementia diagnosis per practice as a proportion of expected diagnosis to reflect the UK Government definition of 'diagnosis rate'. Reported dementia diagnosis was taken from primary care disease registers of the QOF. Expected dementia diagnosis was calculated using the prevalence calculator commissioned and used by NHS England (NHS England, 2013). The dementia prevalence estimates used in the calculator model are taken from an expert panel commissioned by the Alzheimer's Society, United Kingdom (Knapp *et al*., 2007). The model has been constructed using estimates of the prevalence of dementia associated with the age and gender profiles of the GP populations and the proportion of people in residential care homes.

We chose the independent variables to explore their association with dementia diagnosis rates that had been previously identified in the diagnosis of other diseases in England. The type of primary care contract was taken from the Health and Social Care Information Centre (HSCIC) (General Medical Services contract (GMS) is a standard national contract, Personal Medical Services contract (PMS) and Alternative Provider Medical Services contract (APMS) contracts are individually negotiated by practices and local funders and Primary Care Trust Medical Services contract (PCTMS) is a standard localised contract). Practice list size, overall QOF score and GP experience data were also taken from HSCIC. Index of Multiple Deprivation (IMD) scores for each practice were sourced from Public Health England data. The IMD estimates an average deprivation score proportionally across a practice population. Patient-reported access measures were taken from the National General Practice Patient Survey, which is weighted to reflect the demographics of the practice population. Further details of each variable and data source are provided in Table 1.

Statistical analysis

As our outcome measure, dementia diagnosis rates, was positively skewed we used median (quantile) regression models to explore associations between diagnosis rates and selected variables (Kroenker and Hallock, 2001; Katz, 2011). We performed univariate analysis and included any variables with statistically significant associations ($P < 0.05$) into a multivariable model.

We tested for correlation between factors within the multivariable model and linearity in continuous variables. None of the correlations exceeded our

https://doi.org/10.1017/S146342361700007X Published online by Cambridge University Press

Table 1 Data sources of patient and practice variables

Variable	Description	Source	Date	Number of practices	Excluded for missing data
Index of multiple deprivation score per GP practice	Composite score across several deprivation domains. Calculated per GP practice using postcodes of practice population mapped to LSOA. Data categorised into quintiles	National General Practice Profiles at http://fingertips.phe.org.uk/ profile/ general practice produced by Public Health England	2011	7940	229
Average experience of GPs	Years of NHS reckonable service of all GPs in each practice totalled and then an average calculated per practice in units of decades	The Health and Social Care Information Centre Indicator Portal https:// indicators.ic.nhs.uk data taken from 'Exeter' system	September 11	8204	493
% of overall QOF performance	Total QOF points as a percentage of the total available per GP practice. Data categorised into quintiles	National General Practice Profiles at http://fingertips.phe.org.uk/ profile/ general practice produced by Public Health England	April 11	7937	224
Type of primary care contract	Type of primary contract held with commissioner per GP practice. GMS is standard national contract. PMS is individually negotiated by practices. APMS and PCTMS were combined into 'other' due to small numbers	The Health and Social Care Information Centre Indicator Portal https:// indicators.ic.nhs.uk data taken from 'Exeter' system	September 11	8316	605
GP practice list size	Number of registered patients with each GP practice. Data categorised into five ordinal groups	NHS England Dementia Prevalence Calculator version 3. Downloaded from www.primarycare.nhs.uk	2011	7795	84
Accessing care and making appointments (patient reported)	Patient-reported measures of accessibility of practice. Measured in GP patient survey as percentage of respondents answering positively. Domains of accessing care and making appointments only included	The Health and Social Care Information Centre Indicator Portal https:// indicators.ic.nhs.uk data taken from 'Exeter' system	2011–12	8258	547
Accessing care – composite score for all domains (patient reported)	Patient-reported measures of accessibility of practice. Measured in GP patient survey as percentage of respondents answering positively. Composite score for all access domains	The Health and Social Care Information Centre Indicator Portal https:// indicators.ic.nhs.uk data taken from 'Exeter' system	2011–12	8258	547
Practice list $\geqslant$ 65 years old	Percentage of registered practice list over 65 years of age	National General Practice Profiles at http://fingertips.phe.org.uk/ profile/ general practice produced by Public Health England	2011	7942	229

NHS = National Health Service; GMS = General Medical Services contract; PMS = Personal Medical Services contract; APMS = Alternative Provider Medical Services contract; PCTMS = Primary Care Trust Medical Services contract.

threshold of >0.7 and $P < 0.05$ and so no interaction terms were included in the multivariable model. We found that only 'QOF performance' did not have a linear relationship with diagnosis rate and so this variable was included in the model as quintiles. All data were collated and analysed using STATA version 12.

Results

Full data were available for 7711 general practices representing 92.7% of the practices in England in 2011 ($n = 8316$). Practices excluded due to incomplete data were more likely to be smaller practices than those included for analysis (mean patient list size 2595 versus 6685). There was some geographical variation in excluded practices, for instance over 10% of London practices were excluded compared with 4% of practices in the South West region of England.

We found wide variation in reported dementia diagnosis rates across the 7711 practices included in this study. The median dementia diagnosis rate was 41.6% of expected rate, and interquartile range was 31.2–53.9%.

All variables except patient-reported access measures were found to be significantly associated with diagnosis rate in univariate analysis (Table 2) and so were included in the multivariable median regression model.

Patient factors associated with dementia diagnosis rates included age and deprivation. Each percentage point increase in the proportion of the

Table 2 Univariate and multivariable regression analysis of primary care practice characteristics and difference in dementia diagnosis rates

		Unadjusted difference in diagnosis rates (%)		Adjusted difference in diagnosis rates (%)	
	n	Coefficient (95% CI)	*P*-value	Coefficient (95% CI)	*P*-value
Practice deprivation quintiles					
1 (least deprived)	1542	Reference	<0.01	Reference	<0.01
2	1542	0.8 (–0.8 to 2.3)		1.1 (–0.6 to 2.8)	
3	1542	3.7 (2.2–5.2)		4.1 (2.4–5.8)	
4	1542	5.2 (3.7–6.7)		5.1 (3.4–6.9)	
5 (most deprived)	1543	7.6 (6.1–9.1)		8.2 (6.3–10.0)	
QOF performance					
1 (lowest QOF%)	1542	Reference	<0.01	Reference	<0.01
2	1541	2.8 (1.4–4.3)		2.9 (1.2–4.6)	
3	1542	2.6 (1.1–4.1)		3.9 (2.2–5.6)	
4	1543	2.6 (1.1–4.1)		4.6 (2.9–6.3)	
5 (highest QOF%)	1543	2.3 (0.8–3.8)		5.3 (3.6–7.1)	
Primary care contract type					
GMS	4321	Reference	<0.01	Reference	<0.01
PMS	3163	2.7 (1.8–3.7)		1.8 (0.7–2.9)	
APMS or PCTMS	227	5.4 (2.6–8.2)		2.4 (–0.9 to 5.7)	
Practice list size					
0–2999	1321	Reference	<0.01	Reference	<0.01
3000–4999	1673	–0.9 (–2.4 to 0.7)		0.1 (–1.6 to 1.9)	
5000–7999	2040	0.5 (–1.0 to 2.0)		1.8 (0.1–3.5)	
8000–9999	1026	2.7 (1.0–4.5)		4.3 (2.3–6.4)	
10 000 +	1651	1.8 (0.3–3.3)		3.5 (1.7–5.4)	
% of Practice list over 65 (per 1% increase)	7711	–0.4 (–0.5 to –0.3)	<0.01	–0.3 (–0.4 to –0.2)	<0.01
Average decades of GP experience	7711	–2.4 (–3.1 to –1.8)	<0.01	–2.1 (–2.9 to –1.3)	<0.01
Patient access – % of patients positive about ease of making appointments (per 1% increase)	7711	–3.5 (–9.1 to 2.2)	0.23	–	–
Patient access – % of patients positive about overall access to the practice (per 1% increase)	7711	5.4 (–2.4 to 13.1)	0.17	–	–

QOF = Quality and Outcomes Framework; GMS = General Medical Services contract; PMS = Personal Medical Services contract; APMS - Alternative Provider Medical Services contract; PCTMS = Primary Care Trust Medical Services contract.

https://doi.org/10.1017/S146342361700007X Published online by Cambridge University Press

practice population over 65 years of age was associated with a 0.3% reduction in dementia diagnosis rate [−0.3%; 95% confidence interval (95% CI) −0.4 to −0.2], on adjustment for other factors. Therefore where the proportion of practices list over 65 differ by 10%, a difference of 3% would be expected in diagnosis rates. Diagnosis rates of dementia were 8% higher in the most deprived quintile of practices, compared to the least deprived (8.2%; 95% CI 6.3–10.0).

Practice factors associated with dementia diagnosis rates included practice size, average GP experience, contract type and QOF score attainment. Compared with the average diagnosis rate in the smallest practices (list size 0–2999 patients), the average diagnosis rate of practices between 8000 and 9999 list size was 4.3% higher (95% CI 2.3–6.4) and the average diagnosis rate of practices over 10 000 list size was 3.5% higher (95% CI 1.7–5.4).

Average GP experience per practice was negatively associated with diagnosis rates. When the average experience increases by a decade, the diagnosis rate in practices decreases by 2.1% (95% CI −2.9 to −1.3).

Compared with diagnosis rates of practices with GMS contracts, practices with PMS contracts had a diagnosis rate that was 1.8% higher (95% CI 0.7–2.9). Practices with other types of contract (PCTMS and APMS) had a diagnosis rate that was 2.4% higher (95% CI −0.9 to 5.7), although there were relatively small numbers of practices in these categories, and this association was not statistically significant in the multivariable model.

Diagnosis rate was higher with increasing QOF performance. The highest quintile of practices by QOF performance had a diagnosis rate that was 5.3% higher (95% CI 3.6–7.1) than the lowest quintile.

As we were concerned about the potential impact of outliers, we tested the effect of outliers on our results. We excluded practices beyond three standard deviations ($n = 82$) and beyond two standard deviations ($n = 174$) and neither the coefficients nor overall factors associated with diagnosis rate were substantially altered.

Discussion

We found patient demographics; age and deprivation, and GP characteristics; experience, list size and QOF performance are associated with variation in dementia diagnosis.

Our results show that practices in more deprived areas have a higher diagnosis rate, confirming findings of a previous study (Connolly *et al*., 2011). This consistent finding suggests an amendment to the NHS England prevalence model calculator may be appropriate. Dementia prevalence and deprivation is a complex relationship. Several studies have found an association between dementia prevalence and higher levels of deprivation (Wilson *et al*., 1999; Versporten *et al*., 2005; Basta *et al*., 2008; De Deyn *et al*., 2011). This may be explained by higher cardiovascular risk factors (Banerjee, 2013) and the cognitive reserve hypothesis (Brayne *et al*., 2010; Meng and D'Arcy, 2012; Matthews *et al*., 2013) where the protective influence of active cognitive function delays the clinical presentation of dementia. Conversely less deprived populations are more likely to live into old age and therefore be at a higher risk of developing dementia, increasing the prevalence. Further exploration of this complex relationship between deprivation and dementia diagnosis rates may assist in improving the prevalence model and in identifying population-based interventions.

Fewer patients with dementia are being diagnosed in smaller practices and in practices with larger proportions of elderly patients. These results suggest that practices with a larger proportion of older patients may not be successfully identifying cases of dementia in amongst the natural deterioration in cognitive functioning of old age. In addition, it may not confer clinical benefit to record dementia diagnosis for patients already in care homes which may explain this association. These factors do, however, provide an opportunity to target resources in these practices to optimise case finding.

A cohort effect could explain practices with older and more experienced GPs less likely to record dementia in electronic medical records. Larger list size may increase documentation of dementia due to increased clinical specialisation in larger practices. The association found with PMS contract type may indicate innovative and proactive approaches exist within these GP practices relating to both contractual and clinical processes that enhance dementia recording. The lack of association with patient access variables is consistent with findings from a study of educational

https://doi.org/10.1017/S146342361700007X Published online by Cambridge University Press

interventions that found patients and their carers had minimal contact with their GP practice (Downs *et al*., 2006).

This study has a number of limitations. First, despite the statistical significance of the associations identified in this study causal relationships cannot be established within this cross-sectional design. Second, we have relied heavily on the dementia prevalence model developed by NHS England to explore dementia diagnosis rates. There are a number of assumptions built into this model that may reduce its accuracy in predicting dementia in the population. The associations we identify could relate more to the prevalence model than to the diagnosing of dementia in GP practices which may well over-estimate prevalence (Matthews *et al*., 2013). Third, although we included data from the majority of GP practices in England (92.8%) some systematic differences between the practices included and excluded do exist, such as list size and geographical variations. The potential for these and other unknown structural factors to have an impact on our results cannot be ruled out. Fourth, data coding in clinical systems for dementia is variable and in some cases quite poor (Russell *et al*., 2013). Our study analyses the number of patients who have a recorded diagnosis of dementia on GP electronic patient records. We cannot demonstrate how reliable this coding is. There may be structural differences in coding practice that could affect these results and the way in which dementia diagnosis was recorded.

Rurality of the practice population may also influence access to the practice. However data on the rurality of GP practices are based on the location of the practice rather than the patients registered with that practice and were therefore not included.

Practice size, age profile, deprivation, QOF performance and GP contract type are all associated with dementia diagnosis. This wide variation we found in dementia diagnosis rates in English GP practices is reflected internationally. Debate about the variation in the detection of dementia in primary care across Europe (De Lepeleire *et al*., 2008) has highlighted the need to better understand the factors associated with this variation in order to incorporate them into systematic case-finding strategies. This study adds to our understanding of this complex process in England. The identification of specific patient factors associated with variations in dementia diagnosis provide potential population level targets for local government and public health organisations (eg, Public Health England) to identify patient groups at risk of dementia. Specific practice factors could be used by commissioners (eg, Clinical Commissioning Groups) to engage with practices where the case finding is lower than expected.

Since 2011, there have been a variety of national targets and incentives to improve dementia diagnosis rates in the United Kingdom. However, these have been widespread schemes, and do not appear to have considered some of the identified factors associated with dementia diagnosis in this study. Our analysis may provide a benchmark level of diagnosis rate by which the recent schemes can be measured both in the United Kingdom and internationally.

Acknowledgements

No funding was received for this research. No conflicts of interest to declare. The authors are grateful to NHS England for giving permission to use data from their Dementia Prevalence Calculator for this study.

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