

# The place for dementia-friendly communities in England and its relationship with epidemiological need

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**Objectives:** The dementia-friendly community (DFC) initiative was set up to enable people living with dementia to remain active, engaged, and valued members of society. Dementia prevalence varies nationally and is strongly associated with the age and sex distribution of the population and level of social deprivation. As part of a wider project to evaluate DFCs, we examined whether there is a relationship between provision of DFCs and epidemiological need.

**Methods:** Dementia-friendly communities were identified through the formal recognition process of DFC status by the Alzheimer's Society and mapped against areas defined by English Clinical Commissioning Groups. We tested whether provision of a DFC was associated with: (1) dementia prevalence, (2) number of known cases, and (3) known plus estimated number of unknown cases.

**Results:** Of the 209 English Clinical Commissioning Group areas, 115 had at least one DFC. The presence of a DFC was significantly associated with number of known dementia cases (mean difference = 577; 95% CI, 249 to 905;  $P = 0.001$ ) and unknown dementia cases (mean difference = 881; 95% CI, 349 to 1413;  $P = 0.001$ ) but not prevalence (mean difference = 0.03; 95% CI, -0.09 to 0.16;  $P = 0.61$ ). This remains true when controlling for potential confounding variables.

**Conclusions:** Our findings suggest that DFC provision is consistent with epidemiological-based need. Dementia-friendly communities are located in areas where they can have the greatest impact. A retrospective understanding of how DFCs have developed in England can inform how equivalent international initiatives might be designed and implemented.

## KEYWORDS

dementia-friendly community, epidemiological need, mapping

## 1 | INTRODUCTION

Dementia-friendly communities (DFCs) are one way in which people living with dementia can remain active, engaged, and valued members

of society. Typically, DFCs adopt a range of approaches to achieve their aims. These include working with people living with dementia to change policies, practice, and services; investing in staff and volunteers to promote dementia awareness and skills in supporting people

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living with dementia; adapting the environment; and ensuring that unpaid carers receive support.

In England, the Prime Minister's Challenge on Dementia 2020 has called for an increase in the number of DFCs.<sup>1</sup> There is a lack of research investigating effectiveness of DFCs, although within the literature a broad consensus exists about the importance of the role DFCs play in raising awareness about and promoting participation among people with dementia.<sup>2</sup> However, there is no single agreed model of what a DFC is, and definitions of "community" and "dementia-friendly" vary greatly.<sup>3</sup> While the elements of a DFC may differ, most have explicit, or at least implicit, geographical boundaries. Those DFCs that are not location based are small in number and usually embedded within a large public or commercial organisation.

The second Cognitive Function and Ageing Study (CFAS II)<sup>4</sup> was a large epidemiological study that found dementia prevalence, the proportion or percentage of a population affected by this condition, to vary between 3.3% and 8.4% among local authority areas in England. The age, sex, and social deprivation profile of an area were factors associated with a higher prevalence of dementia. Dementia-friendly communities have the potential for greater reach where prevalence is higher. However, factors associated with higher prevalence such as greater social deprivation may work against the establishment of DFCs given the need for community resources to initiate and develop them. This study set out to examine whether DFC provision, in terms of a recognised and established DFC initiative, is associated with epidemiologically based need for a given geographical locality in England. For the purposes of our analysis, we use the term "epidemiological-based need" to mean need for a DFC determined by number of cases or number of cases per head of population.

## 2 | METHODS

The analysis presented here is part of the ongoing *National Evaluation of Dementia Friendly Communities (DEMCOM)* study,<sup>5</sup> which aims to develop an evaluation tool and subsequent evaluation of DFCs in England. To understand the growth and distribution of this community engagement initiative, we present an overview by location of DFC provision in England, as of March 2017, and examine how provision is associated with epidemiologically based need in terms of estimated prevalence and number of cases (known and estimated) by locality.

### 2.1 | Data sources

#### 2.1.1 | DFC provision

Dementia-friendly communities were identified through the formal recognition process of DFC status by the Alzheimer's Society, a charitable organisation that supports those affected by dementia in the United Kingdom and funds dementia research. This recognition is granted on the basis of certain criteria such as evidence of leadership and structures and a willingness to address issues that are of concern locally.<sup>6</sup> Communities that were not location based, for example, national organisations such as banks, supermarkets, or online communities who defined themselves by interest rather than location (eg, people with young onset dementia), were excluded from this analysis.

### Key points

- At least one dementia-friendly community was based in 115 of 209 location-based CCGs.
- Number of known and estimated cases of dementia is associated with presence of a DFC.
- In rural areas, geographic reach of the community will determine how well local populations are served by DFCs.
- There was no evidence of an inverse care law in terms of the geographical provision of DFCs.

### 2.1.2 | Epidemiologically based need

Geographical areas were based on the boundaries of English Clinical Commissioning Groups (CCGs). In England, health services are organised into CCGs who have responsibility for planning and commissioning service provision for a geographically defined local area. They are responsible for the health of the entire population in their area and serve populations ranging from approximately 68 000 to 900 000 with a mean population<sup>7</sup> of 226 995. In this study, the presence of dementia by locality was measured in three ways: (1) prevalence, (2) number of known dementia cases based on primary care records, and (3) estimated number of dementia cases.

Dementia prevalence (the proportion of a specified population with dementia) and number of cases known to primary care services for those aged 65 years and over was based on English primary care records and accessed via the Fingertips Toolkit,<sup>8</sup> a publicly available electronic source of key health indicators. Data are uploaded by every general practice and include presence of dementia diagnosis, age, and sex for each registered patient.<sup>9</sup> Each practice receives a financial incentive to report the number and proportion of registered patients with known dementia diagnoses.<sup>10</sup> Data for the estimated number of known and unknown dementia cases for each CCG area were accessed via NHS England.<sup>9</sup> These are calculated using 5-year age-sex group estimates from the CFAS II and applied to the Office of National Statistics (ONS) population projections for people aged 65 years and over.

### 2.2 | Analysis

A map of CCGs in England was produced using ArcGIS software 2016 version 10.4.1. Dementia prevalence data for each CCG were divided into quintiles and overlaid onto the map of CCGs in England. Dementia-friendly communities were added to the maps with a marker representing the geographical centre of each DFC. Three independent *t* tests were performed comparing CCGs with a DFC with CCGs without a DFC in terms of three methods of epidemiological need: (1) dementia prevalence, (2) number of known dementia cases, and (3) estimated number of known and unknown dementia cases.

To adjust for potential confounders and test whether the number of DFCs (rather than simply the presence of one or more) within a CCG area was associated with any of the three measures of dementia prevalence, three ordinal regression models were used. In these

models, the outcome was number of DFCs within a CCG categorised into three levels (zero, one, two or more). Potential confounders were population size of CCG area and mean deprivation score as measured by the English indices of deprivation, a relative measure of deprivation.<sup>11</sup> Social deprivation was not included as a covariate in the model examining the estimated number of known and unknown cases of dementia. This model uses estimates produced from CFASII data, which already takes into account the social deprivation of a given area. We tested the proportional odds assumption using likelihood ratio tests. Where there was evidence the proportional odds assumption was violated, we reverted to binary outcomes using logistic regression models. All analysis was conducted using Stata<sup>12</sup> version 14.2.

### 3 | RESULTS

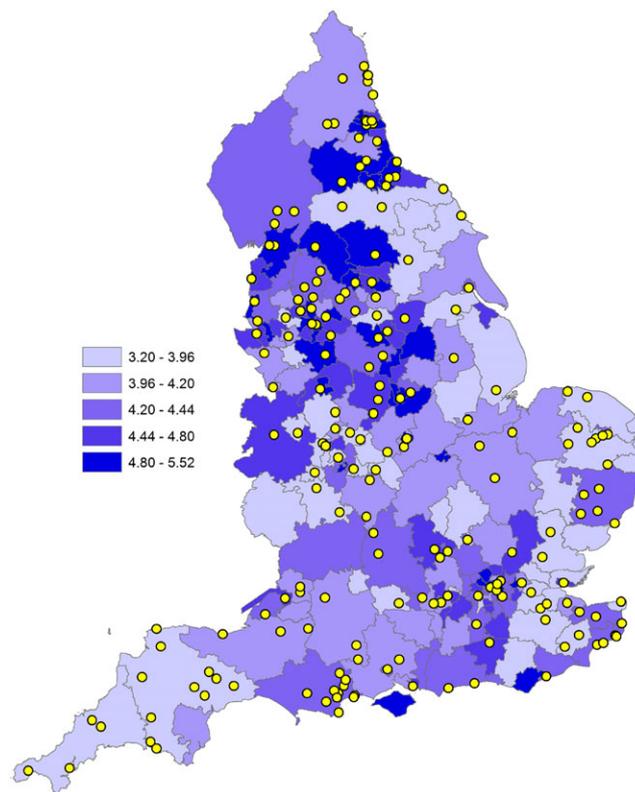
We identified 196 DFCs that had been formally recognised by the Alzheimer's Society. Seven communities were identified that were not location based but organisation based spanning a much wider area or national in scope. These were not possible to map and therefore excluded from further analysis. At the time of the study, there were 209 CCGs in England. Of those, 94 had no DFC, 77 had one DFC, and 38 had two or more DFCs. The maximum number of DFCs for one CCG was 11. Dementia prevalence based on primary care records ranged from 3.2% to 5.5%. Taking account of both known and unknown dementia cases, the mean estimated number of dementia cases for these 209 CCGs was 3057 (SD = 1986).

Dementia-friendly communities were located throughout England (Figure 1) from the south-westernmost corner to the north-east coast. Concentrations appear to be in London and the South East and from the Midlands up to the conurbations of the North West. When mapped against prevalence of dementia, CCG areas with higher prevalence appear to benefit from DFC initiatives. However, there was no statistical evidence of a difference in dementia prevalence between those CCG areas with (n = 115) and without (n = 94) a DFC ( $P = 0.61$ ; see Table 1). This remained true after adjustment with the odds of a DFC being present in a CCG area 0.76 times that with an increase in 1% prevalence (95% CI, 0.40 to 1.47;  $P = 0.42$ ).

In contrast, when comparing CCG areas with and without a DFC in terms of unknown cases of dementia, there was evidence to suggest that areas with higher predicted cases of dementia had better provision of DFC initiatives (mean difference = 881; 95% CI, 349 to 1413;  $P = 0.001$ ). This was still true when analysis was restricted to known cases of dementia reported in primary care records (mean difference = 577; 95% CI, 249 to 905;  $P < 0.001$ ) as shown in Table 1. In adjusted analysis, the increased odds of a DFC (zero to one, one to two or more) were 3.87 (95% CI, 2.13 to 7.02;  $P < 0.001$ ) and 1.87 (95% CI, 1.36 to 2.58;  $P = 0.001$ ) per 1000 people with a dementia diagnosis and per 1000 people estimated to have dementia, respectively.

### 4 | DISCUSSION

Thus far, much of the research examining DFCs has been conceptual rather than empirical.<sup>2,13</sup> This examination of provision and



**FIGURE 1** Prevalence of dementia (%) from primary care records by Clinical Commissioning Group and Dementia-Friendly community location (yellow dot) as of March 2017 [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

epidemiological need and the wider DEMCOM study currently underway is an attempt to address that gap. The United Kingdom and Japan are the only two countries with a formal nationwide programme of targeting communities to enable people with dementia to live active and integrated lives within them.<sup>14</sup> A retrospective understanding of how DFCs have developed in England can inform how equivalent international initiatives might be designed and implemented.

In our study, at least one DFC was based in 115 of 209 location-based CCGs. As with other Western countries,<sup>15</sup> DFCs in England are now spread throughout the country in urban and rural areas. The presence of a DFC is associated with number of dementia cases (known and unknown) but not the proportion of the population with dementia (prevalence). It is unclear whether association with number of cases is a function of DFCs responding to epidemiological need, but adjustments in our analysis for population size suggest that it is not simply the case that DFCs have emerged in areas with greater population density.

A limitation of this study is that DFC provision is treated as a fixed geographical point when some CCG areas may benefit from proximity to a DFC located in a neighbouring area. Dementia-friendly communities typically have a city or town centre, but their reach or the extent to which they penetrate the surrounding area may vary greatly. The very notion of "place" presupposes the existence of boundaries that are often determined by the source and conditions of funding. There is perhaps an inherent contradiction between dementia friendliness and rigid or nonpermeable boundaries. It is plausible that concentration of DFC effort weakens with greater distance from its natural

**TABLE 1** Unadjusted and adjusted associations of DFCs and measures of epidemiological-based need

	Unadjusted Analysis			Adjusted Analysis				
	DFC Present in CCG Area n = 115 (Mean (SD))	DFC not Present in CCG Area n = 94 (Mean (SD))	Mean Difference (95% CI)	P Value <sup>a</sup>	0 vs 1 vs 2+ DFCs Present in CCG Area <sup>b</sup> OR (95% CI)	P Value <sup>d</sup> (Prop Odds)	Logistic Regression Model OR (95% CI)	P Value <sup>e</sup>
Dementia prevalence (%) (QOF)	4.35 (0.45)	4.38 (0.47)	0.03 (-0.09 to 0.16)	0.61	0.76 (0.41 to 1.39)	0.36	0.76 (0.40 to 1.47)	0.42
Number with a dementia diagnosis (n) (QOF)	2326 (1404)	1749 (877)	577 (249 to 905)	<0.001	3.87 (2.13 to 7.02)	<0.001		0.11
Number estimated to have dementia (n) (CFAS II) <sup>f</sup>	3453 (2299)	2572 (1382)	881 (349 to 1413)	0.001	1.87 (1.36 to 2.58) <sup>g</sup>	<0.001		0.13

Abbreviations: CFAS, Cognitive Function in Ageing Study; CCG, Clinical Commissioning Group; DFC, dementia-friendly community; QOF, Quality Outcome Framework; SD, standard deviation.

<sup>a</sup>Unpaired t test.

<sup>b</sup>Odds ratios from ordinal logistic regression model.

<sup>c</sup>P value from ordinal logistic regression model.

<sup>d</sup>Likelihood ratio test of proportionality of odds.

<sup>e</sup>P value from logistic regression model.

<sup>f</sup>Odds ratios are based on increased odds of higher number of DFCs per 1000 people with dementia.

<sup>g</sup>Social deprivation not entered into the models due to being controlled for in the CFAS II estimates.

centre. However, a study of DFCs in rural Canada suggested that rural communities may have the advantage of familiarity that allows members to remain connected<sup>11</sup> and there are recognised challenges for older people living in urban environments.<sup>16</sup> The use of primary care data to determine number of cases can be problematic in that dementia may be underrecognised and underreported.<sup>17</sup> There is evidence that the identification of dementia cases from routine health records has high positive predictive value and reasonable sensitivity.<sup>18</sup> By using CFAS II estimates specific to CCG area, we have been able to include estimates of unknown cases.<sup>4</sup>

We found no evidence of an inverse care law,<sup>19</sup> at least in terms of geography, whereby provision is better for those with least need. The process of mapping the provision of DFCs does not tell us how or even if this initiative has an impact on people affected by dementia. It does suggest that the very idea of DFCs has resonance, witnessed by rapid growth, national coverage, and support of government policy and charitable organisations. Whether this growth is matched by sustainability remains to be seen; DFCs are reliant on local participation<sup>20</sup> and stakeholder involvement, both of which are unpredictable and changeable.<sup>21</sup>

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## CONFLICT OF INTEREST

None declared

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