

# Undiagnosed dementia in primary care: a record linkage study

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## Scientific summary

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# Scientific summary

## Background

Dementia is a syndrome of progressive loss of cognitive and everyday functional ability. It is associated with a number of underlying brain pathologies, including Alzheimer's disease-type pathologies, cerebrovascular disease and Lewy body disease among many others. Memory impairment is a characteristic of Alzheimer's disease, but other dementias, particularly those presenting at younger ages, can have an early natural history with different profiles of cognitive impairment and non-cognitive symptoms, including psychosis, personality changes and behaviour changes.

Dementia has enormous social and economic impact and is a major cause of disability and death. Dementia is more common in the older population and after the age of 65 years the incidence of dementia roughly doubles every 5 years.

In January 2018, NHS Digital estimated the number of people aged > 65 years with dementia in England to be 645,101. However there were only 438,142 coded dementia diagnoses among those aged > 65 years at that time (NHS Digital. *Recorded Dementia Diagnoses, January 2018*. 2018. URL: <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/january-2018>; accessed 12 July 2017). This suggests that a significant number of people who are living with dementia have not been diagnosed. Over the past decade, this 'dementia diagnosis gap' has been the focus of considerable attention in health services worldwide, with case-finding strategies employed to increase the number of diagnoses as a proportion of the estimated number of cases in the population. However, a formal diagnosis of dementia has a spectrum of potential benefits and harms to the individual that are poorly understood. There is also little known with respect to the characteristics of those living with undiagnosed dementia and little quantitative evidence for the person-level characteristics that facilitate or prevent people with dementia from seeking help or receiving a diagnosis. The distribution of the time taken between meeting the criteria for dementia and being diagnosed is also not known, which has implications for researchers using dementia diagnosis in primary care as a proxy for dementia incidence.

## Aims and objectives

Our broad aim was to describe the population with undiagnosed dementia in England; to identify the predictors of help-seeking and diagnosis; to describe the rate of new diagnoses among the population without a dementia diagnosis; and to estimate the effect of being diagnosed on several important outcomes.

Specific research questions were as follows:

- What was the prevalence of undiagnosed dementia between 2008 and 2013?
  - What proportion of those with undiagnosed dementia had a general practitioner record of cognitive complaint/impairment?
  - How many had been referred to specialist services and how many had no record of any cognitive impairment?
  - What are the social and clinical characteristics of the population without dementia but with a dementia diagnosis recorded in primary care?

- What are the associations between social and clinical characteristics of a person with dementia and their risk of being undiagnosed?
- What is the incidence of new diagnosis among the population with undiagnosed dementia?
- What are the predictors of getting a diagnosis among people with undiagnosed dementia?
- How are clinical, psychosocial and health-care utilisation trajectories over a 2-year follow-up period associated with diagnosis status among people with dementia?

## Methods

This was a data linkage study, linking interview and assessment data from the Cognitive Function and Ageing Study II (CFAS II) with participants' primary care records.

CFAS II is a large epidemiological study of a cohort of people aged  $\geq 65$  years that is representative of the population in England. CFAS II recruited 7796 people from Nottingham, Newcastle and Cambridgeshire and carried out in-depth interview and assessment. For each person, independently of health services, CFAS II assessed dementia status at baseline [wave 1 (W1), 2008–11] and at 2-year follow-up [wave 2 (W2), 2011–13], applying the Geriatric Mental State-Automated Geriatric Examination for Computer Assisted Taxonomy algorithm to data from patient and informant interviews. In total, 634 people were assessed to have dementia in at least one of their interviews, 449 of whom also gave consent to use their medical records for research.

Therefore, CFAS II provided a population-representative sample of people with dementia status determined independently of health-care services, with detailed information on the clinical characteristics and social circumstances of each participant. Consent to extract medical records provided an opportunity to link and compare the standardised and validated CFAS II assessments of dementia status to diagnoses, referrals to memory services and cognitive concerns in the patient's primary care record.

Participants were included if they were:

- existing participants of CFAS II; and
- had provided consent to use medical records and consent for data to be held long term and used for research purposes, including in the event of the participant's incapacity or death; and
- had a study diagnosis of dementia or were a selected participant without dementia.

They were excluded if consent had been withdrawn at any point.

The general practice with which each person was registered at the time of first meeting the CFAS II criteria for dementia was identified. Data from their primary care record, including the fact and date of recorded cognitive concerns, referral and dementia diagnoses, were requested. Data from medical records were linked to CFAS II assessment and interview data. Additional data on mortality and area-level deprivation were also transmitted from the CFAS II team.

Using this data set, we estimated the distribution of primary care diagnosis status across subgroups stratified by sociodemographic and clinical factors, and conducted multivariable analyses to identify the independent predictors of being diagnosed among the population with dementia.

Time to record of primary care diagnosis or death from first meeting the clinical criteria for dementia was estimated using competing risks time-to-event analysis. Cox proportional hazards regression was used to estimate predictors of new diagnosis for up to 2 years among people with undiagnosed dementia.

Cox regression was also used to estimate the effect of diagnosis on survival adjusting for covariates. Multinomial logistic regression was used to estimate the effect of diagnosis on changes between interview waves in generalised anxiety, health-related worry and the number of social activities undertaken by participants, adjusting for cognitive function, age, sex and living arrangement. All analyses were carried out using Stata® 14.1 (StataCorp LP, College Station, TX, USA).

## Results

From CFAS II, we identified 449 people with dementia who met the inclusion criteria and selected 149 people without dementia who met eligibility criteria. Of the requested medical records, 94% were returned, all of which met data entry validation criteria.

### *Distribution of primary care diagnosis status among people with and without dementia*

The proportion of people with dementia who had a diagnosis in their primary care record rose from 34.8% for CFAS II W1 (2008–11) to 43.2% for W2 (2011–13). This difference was statistically significant in multivariable analysis [odds ratio (OR) 1.68, 95% confidence interval (CI) 1.07 to 2.64]. At both time points, around 21% of people with dementia had a cognitive concern or referral for cognitive concern noted, but had not received a diagnosis. Hence, a substantial but falling proportion of people with dementia had no record of any concern regarding cognitive function, referral or diagnosis in their medical record. There were very few people with a diagnosis of dementia in the primary care record who did not meet the CFAS II criteria for dementia.

### *Predictors of having a recorded diagnosis among people with dementia*

Among people with dementia, having a recorded diagnosis was very strongly associated with increased severity of impairment in memory and orientation, but not with severity of impairment in other cognitive domains.

Informants' perception of a participant's memory impairment is a substantial independent predictor of diagnosis (independent of objectively measured cognitive impairment), as is the number of non-cognitive symptoms reported, albeit to a lesser extent.

Dementia diagnosis was less commonly recorded among participants with extensive cardiovascular comorbidity (four or five comorbidities compared with none; OR 0.15, 95% CI 0.03 to 0.78), but other physical comorbidity and comorbid depression or anxiety were not linked to the likelihood of being diagnosed.

People with dementia living with a long-term partner were around twice as likely to be diagnosed than those in other living arrangements (OR 2.20, 95% CI 1.20 to 4.01, compared with those in a residential care setting); they were also likely to more likely to seek help (OR 1.97, 95% CI 1.09 to 3.55). People with dementia aged  $\geq 90$  years were less likely to be diagnosed than those aged 75–89 years. There was no evidence that the likelihood of diagnosis was linked to area-level deprivation or maximum educational attainment of the participant.

### *Time to diagnosis and predictors of time to diagnosis among people with dementia*

The median time to clinical diagnosis from the time at which a participant meets clinical criteria for dementia was around 3.5 years. However, this time varied greatly: many were diagnosed close to the point that they first met the CFAS II criteria for dementia, yet at 6 years after meeting CFAS II criteria around 20% were still alive and undiagnosed and a further 20% had died without being diagnosed. Analysis of the time to new diagnosis among those who were undiagnosed at their CFAS II assessment date suggests that men, those in the youngest and oldest age groups and those in residential care were least likely to become diagnosed.

### **The consequences of diagnosis**

There was no evidence that being diagnosed affected subsequent mortality or delayed moving to a residential care setting. Data on changes in social contact, mood and inpatient hospital visits were extremely limited.

### **Strengths and limitations**

This study was based on a large population-representative cohort, with an objective and independent dementia status based on a validated algorithm, and with data on a wide range of other social and health-related characteristics. To our knowledge, it is the largest study to examine prevalence, causes and consequences of diagnosis among people with dementia. However, the study does have several important limitations.

Although the response rate from general practices was extremely high, a substantial proportion of participants with moderate to severe dementia at W1 could not consent to the use of their medical records; and the CFAS II itself has a response rate of 56%. Weights and multiple imputation were used as appropriate to reduce the impact of these missing data on estimates.

Diagnosis status was extracted from primary care records by practice staff or Clinical Research Network nurses. Although the data were validated with respect to the correct individual being identified, the data entry was not independently verified. Data on some covariates relied on report from the participant themselves, a proxy or informant, and so may not have been reliable.

Few participants fell into the group that were not diagnosed but had some record of cognitive concern in their primary care record, and so it was difficult to draw strong conclusions about this group, or to identify separate predictors of help-seeking and diagnosis conditional on help-seeking. Likewise, the sample size for estimation of predictors for those with undiagnosed dementia but diagnosis in the subsequent 2 years is also small (based on only 66 new diagnoses).

A substantial proportion (66%) of those with dementia at W1 did not return to the study at W2, which is unsurprising as many had severe dementia at baseline. Although we did have complete follow-up information on mortality for all participants, we were not able to determine changes in other outcomes among this group.

The CFAS II took place against a backdrop of policy change and increased focus on dementia diagnosis.

### **Conclusions**

The number of people with diagnosed dementia in the UK rose between 2008 and 2013. The proportions of Cognitive Function and Ageing Study II Dementia Diagnosis Study (CADDY) participants diagnosed with dementia in the periods 2008–11 and 2011–13 were consistent with those reported by the Health and Social Care Information Centre (now NHS Digital), with little evidence of substantial numbers of false-positive diagnoses.

The lack of association between diagnosis and the level of impairment in cognitive domains other than memory and orientation suggests that people with dementia but without substantial impairments in memory are much less likely to be diagnosed. This could reflect a lack of awareness of non-memory symptoms of dementia, a deficiency in diagnostic process in cases in which memory is less affected.

There remains little quantitative evidence for the effect of diagnosis for a person with dementia. Without this, any future screening or case-finding programme would be difficult to justify. It is likely that the effect of diagnosis will depend heavily on individual characteristics of the person with dementia and the support available to them.

Understanding the average time between dementia incidence and a diagnosis being recorded in primary care is important for researchers using recorded dementia diagnosis as a proxy for dementia incidence, or those selecting people with dementia based on the presence of a clinical diagnosis. Epidemiological studies such as CFAS II are essential for describing the population with chronic disease without the bias associated with differential rates of help-seeking and diagnosis across subgroups of the population.

## Implications for practice

- Dementia can be a complex and difficult disease to diagnose and there is a gap for many people between having manifest signs of dementia and having a diagnosis of dementia recorded in primary care.
- Non-memory presentations of dementia appear to be more readily overlooked. This could be evidence of a gap in public and clinical awareness of other symptoms of dementia.
- People with dementia aged  $\geq 90$  years, those living alone and those with comorbidity may also be underdiagnosed, and practitioners should be aware of the possibility of undiagnosed dementia among these groups.

## Recommendations for research

- At present, there is little quantitative objective evidence that obtaining a diagnosis improves patient outcomes. This may reflect the shortcomings of current post-diagnostic support, but also the lack of studies specifically designed to quantitatively explore the diagnostic pathway and estimate the effect of dementia diagnosis on patient outcomes. Further research with longer and more systematically measured follow-up is required to bridge this evidence gap.
- Researchers should be keenly aware of the large average lag and large variation in the distribution of the time between dementia incidence and the time to diagnosis of dementia in primary care, particularly when the first record of a dementia diagnosis is used as the basis for recruitment or as a proxy for dementia incidence in epidemiological studies.

## Study registration

CADDY is registered with the National Institute for Health Research Clinical Research Network Central Portfolio Management System (CPMS 30655).

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