**Undiagnosed dementia**

**Prevalence, causes and consequences**

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**Undiagnosed dementia**

The number of diagnosed cases of dementia is much lower than the number of people estimated to be living with dementia in the population.

As the exact prevalence of dementia is not known it is hard to say how many people have undiagnosed dementia. Not much is known about people with undiagnosed dementia, or what the benefits or harms of diagnosis are.

**Our study will...**

Provide new information on the proportion of people with living with dementia who are at different stages of the diagnostic process, estimated directly in this population.

Explore how demographic, socio-economic, and clinical factors affect help-seeking, referral and diagnosis.

Compare future clinical, psychological and healthcare utilisation data across groups.

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**Why is diagnosis not made?**

We began by reviewing literature and asking representatives of patient and public involvement (PPI) groups to help us to understand why diagnosis might not be made.

Previous qualitative research has suggested many factors that could affect whether or not a person with dementia seeks or receives a formal diagnosis.

Many of these factors are related to disease, subjective experience and social circumstances. They will be empirically tested using our data.

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**Preliminary Findings 1: How many people have undiagnosed dementia?**

Preliminary findings suggest that between 2009 and 2011 34% of the population with dementia had been formally diagnosed, with this rising to 42% two years later.

This supports indirect national estimates of diagnosis rate during this time; we found that in both time periods a further 20% of people with dementia had a record of some cognitive complaint, of whom around half had been referred to specialists but were not yet diagnosed.

This leaves a large although declining proportion having no mention at all of any cognitive impairment or complaint in their primary care record (‘unknown’). 

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**Preliminary Findings 2: Who is most likely to remain undiagnosed?**

People with dementia living in long term care institutions are no more or less likely than those living at home to be diagnosed (after adjusting for dementia severity). However for those living at home the diagnosis rate is lower among people living alone compared to those living with a long term partner (e.g. spouse).

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**Methods: Linking primary care records to data from the Cognitive Function and Ageing Study II (CFAS II)**

CFAS II provides the most up to date and reliable estimates for the prevalence of dementia in England. CFAS II recruited participants at random, irrespective of their health or cognitive status from three areas of England. 7796 people aged 65 years and older were assessed, and a ‘study diagnosis’ of dementia status was made for each by the CFAS II research team. At the time of assessment, participants were also asked to consent to medical record linkage. 458 participants with dementia consented to this linkage.

**CFAS Dementia Diagnosis Study (CADDY)**

Between 2016 and 2017 we asked the GPs of participants with a study diagnosis of dementia and who consented to linkage:

- whether or not a diagnosis of dementia was recorded in their GP record,
- to describe the process of presentation with a cognitive complaint,
- details of referrals to specialist services and subsequent findings.

To date we have a 90% response rate from GPs.

Here we present preliminary analysis of our data to date.

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