Aims and Methods
The number of diagnosed cases of dementia is much lower than the number of people estimated to be living with dementia in the population. Little is known about people with undiagnosed dementia, or what the effects of diagnosis would be in this group. By linking primary care records with epidemiologic cohort study data we can explore many aspects of the undiagnosed population and the diagnostic process.

Methods: Linking primary care records to data from the Cognitive Function and Ageing Study (CFAS) II
CFAS II provides the most up to date and reliable estimates for the prevalence of dementia in England. CFAS II recruited participants using random sampling irrespective of their health or cognitive status from three areas of England.

Two waves of interviews were conducted, wave 1 between 2009 and 2011 and wave 2 between 2011 and 2013. Dementia assessments were conducted at each wave. See www.cfas.ac.uk for more information on the Cognitive Function and Ageing Studies.

In total 7796 people aged 65 years and older were assessed, and a ‘study diagnosis’ of dementia status was made for each. At the time of assessment, participants were 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 primary care provider of people with dementia who consented to linkage:
• whether or not they had been diagnosed with dementia;
• to describe the process of presentation with a cognitive complaint;
• details of referrals to specialist services and subsequent investigations.

Data on diagnosis status was available for n=412 participants (90% response rate from primary care providers) with dementia of whom 232 (56%) had ever received a formal diagnosis. A ‘control’ sample of around 300 people without dementia was also included, to explore the rate and characteristics of those with ‘false positive’ diagnosis in their primary care record.

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First Findings
Median time between meeting criteria for dementia and diagnosis in primary care is 3 years
The graph shows the cumulative incidence of dementia diagnosis, and the competing risk of death before diagnosis for the cohort who first met the study criteria for dementia between at wave 2 (incident cases between waves 1 and 2). At approximately 6 years after dementia incidence 60% of people with dementia were diagnosed, 20% had died before diagnosis and 20% remained alive but had not been diagnosed.

Diagnosis did not reduce subsequent days of inpatient hospital admission
People with undiagnosed dementia are more likely to be living alone than those with diagnosed dementia
As expected people with more severe dementia (as measured by CAMCOG) are more likely to be diagnosed. However among CAMCOG subdomains only memory and orientation are linked to diagnosis. Severity of deficits in language, praxis or abstract thinking does not independently predict who is diagnosed (not shown)

Conclusions and Next steps
We have established a cohort study of people with dementia including those known and unknown to healthcare services, and with longitudinal social, clinical, demographic, health care utilisation, mortality and diagnostic pathway data. This will enable a thorough exploration of:
• The characteristics of the population with undiagnosed dementia.
• Determinants and consequences of missed diagnosis.
• The prevalence and characteristics of ‘false positive’ diagnoses recorded in primary care.

Full findings launch and workshop
12 December 2017 "Dementia Diagnosis Research, Policy and Practice"
Royal College of General Practitioners
30 Euston Square, London, UK
contact caddy@uea.ac.uk for event updates, registration details and further information