

Dementia undetected or undiagnosed in primary care: the prevalence, causes and consequences

<https://www.neurodegenerationresearch.eu/survey/dementia-undetected-or-undiagnosed-in-primary-care-the-prevalence-causes-and-consequences/>

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Dementia undetected or undiagnosed in primary care: the prevalence, causes and consequences

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The project/programme is most relevant to:

Alzheimer's disease & other dementias

Keywords

Research Abstract

Background Between 600,000 and 800,000 people in England have dementia, yet only around 344,000 are recorded on dementia registers maintained by GPs. So a substantial proportion of

people with dementia do not have a diagnosis. Closing this diagnosis gap is an NHS and Department of Health priority, but very little is known about the population with undiagnosed dementia, and there is little direct evidence regarding the benefits of a dementia diagnosis. Aims We will link data from an existing longitudinal cohort study (Medical Research Council Cognitive Function and Ageing Study; CFAS II) with primary care records to estimate the prevalence of undiagnosed dementia and its distribution among the older population of England, the barriers to diagnosis and the clinical and psychosocial impacts of diagnosis among people with dementia. Methods and research questions Around 460 participants of CFAS II received a study diagnosis of dementia between 2008 and 2012 and gave consent for their medical records to be examined. CFAS II is designed such that these participants are representative of the English population aged 65 and older with dementia. We will contact their GPs to ascertain whether dementia was suspected, diagnosed or recorded on dementia registers at the time of study diagnosis. CFAS II assessments include: • A comprehensive cognitive assessment • Informant reports of psychiatric and medical comorbidity (including history and treatment) and functional impairment • Behavioural and psychological assessment • Social participation and contacts • GMS/AGECAT dementia diagnosis: a widely used algorithmic dementia diagnosis, validated against Diagnostic and Statistical Manual (DSM) definitions and upon which many UK and global dementia prevalence estimates are currently based. From GP records we will extract and link: • Fact and date of dementia diagnosis and presence on QOF dementia registers • First mention of memory/cognitive impairment • Referrals to dementia services • Censoring events By combining these data we will answer the following questions: Primary objectives: • What was the prevalence of undiagnosed dementia between 2008 and 2012? • What are the associations between social and clinical characteristics of a person with dementia and their risk of being undiagnosed? • To what extent does the dementia register mandated by the quality outcomes framework (QOF) reflect GPs knowledge of cognitive impairment among their patients? Secondary objectives: • How are clinical and psychosocial trajectories over a two year follow-up period associated with diagnosis status among people with dementia? Dissemination and Impacts Our dissemination plan is designed to reach all relevant stakeholders to inform the policy debate around dementia diagnosis and the design and implementation of plans to achieve timely diagnosis of dementia for all. Timetable This work is expected to take 24 months. Months 1-5: Develop and pilot a data collection protocol, refine analysis objectives. Months 6-12: Data collection phase. Months 13-24: Data linkage, quality assurance, analysis, dissemination activities.

Lay Summary

Further information available at:

Types:

Investments > €500k

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United Kingdom

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Alzheimer's disease & other dementias

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Database Categories:

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