

Supplementary Information

Title: Evaluation of routinely collected records for dementia outcomes in United Kingdom (UK): a longitudinal study.

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Methods

Dementia ascertainment and diagnostic codes in hospital, death records and mental healthcare data

Individuals were followed from the date of consent, until the earliest date of a dementia diagnosis or date of death in or after 1996 when formal follow up by health records began in EPIC-Norfolk. To maximise the outcome data, we included any-cause dementia, the sub types of dementia were not analysed separately. Participants with no reports of death or dementia were censored on 31st December 2018. Dementia from HES records, death certificate or the MHDS was defined as any of the ICD-10 codes as listed in Supplementary Table S1.

Dementia case ascertainment through GP records

The protocol was based on a 'clean up' exercise [1] recommended by clinical commissioning groups (NHS bodies that commission services for defined populations) to improve dementia diagnosis in general practices. [2] We employed Read codes (Supplementary Table S1) identified as most commonly used for a dementia diagnoses. [1] Twenty-six collaborating GP practices were invited to participate. Those practices that agreed to take part in this exercise were provided with a detailed protocol and a list of patients on their register who were also EPIC-Norfolk participants. Each practice ran searches to generate lists of these respondents to establish which had a dementia diagnosis code, or were prescribed dementia defining medication, Donepezil, Galantamine, Rivastigmine or Memantine as identified by the relevant Read code (Supplementary Table S1).

Data were returned via a secure transfer system. Practices were also asked to complete a simple questionnaire. The full protocol and sample questionnaire are available on request. Practices were advised to take advantage of this exercise by comparing results of the search against their Quality and Outcomes Framework (QOF) [3] dementia register to check for discrepancies to improve their dementia diagnosis rates. [1] QOF for dementia coding in primary care financially incentivises each recorded dementia diagnosis.

In the second phase, cases identified from GP records were cross-checked with the NHS Digital data, and the level of agreement between the data sources was examined. GP records of individuals with a dementia diagnosis in secondary care but missing from the initial GP data extract were further reviewed by researchers in the third and final confirmation phase of this study. Individual records were reviewed by the researchers for any dementia read or ICD code or mention of dementia as free text. Initial case ascertainment from GPs was conducted between 2016-2017 and NHS Digital data were up to 31st March 2018, with case confirmation in GP records up to 20th December 2018, allowing few months after the follow-up period for the NHS Digital (secondary care) data.

Co-variates included in analyses

Education (the highest level attained) and social class were obtained from the baseline questionnaire. Education was categorised into three groups (i) No qualification (not completing school up to the age of 16), (ii) Completion of school up to the age of 16 or up to the age of 18 and finally (iii) those obtaining an education to graduate level (those who obtained a degree or equivalent) or above.

Social class was classified according to the Registrar General's occupation-based classification scheme into five main categories. [4] Social class I consists of professionals, class II includes managerial and technical occupations, class III is subdivided into non-manual and manual skilled workers (III non-manual and III manual), class IV consists of partly skilled workers, and class V comprises unskilled manual workers.

Table S1: Read and ICD 10 codes used in EPIC-Norfolk to search for 'Definite' dementia cases

Read codes	ctv3_codes	Read Code Description	ICD Code	ICD Description
Eu00	Eu00	Dementia in Alzheimer's disease	F00	Dementia in Alzheimer's disease
			G30	Alzheimer's disease
Eu000		Dementia in Alzheimer's disease with early onset	F00.0	Dementia in Alzheimer's disease with early onset
			G30.0	
Eu001	X0030	Dementia in Alzheimer's disease with late onset	F00.1	Dementia in Alzheimer disease with late onset
	XaIKC	Alzheimer's disease with late onset	G30.1	
Eu002	Eu002	Dementia in Alzheimer's disease, atypical or mixed type	F00.2	Dementia in Alzheimer disease, atypical or mixed type
			G30.8	Other Alzheimer's disease
F110		Dementia in Alzheimer's disease, unspecified	F00.9	Dementia in Alzheimer's disease, unspecified
Eu01	XE1Xs	Vascular dementia	G30.9	
			F01	Vascular dementia
			F01.0	Vascular dementia of acute onset
Eu011	Xa0IH	Multi-infarct dementia	F01.1	Multi-infarct dementia
Eu012	X003T	Subcortical vascular dementia	F01.2	Subcortical vascular dementia
Eu01y	Eu01y	Other vascular dementia	F01.8	Other vascular dementia
Eu01z	Eu01z	Vascular dementia, unspecified	F01.9	Vascular dementia, unspecified
			F02	Dementia in other diseases classified elsewhere
Eu020/F111	X0034/F111	Picks Disease (Read)/Frontotemporal dementia includes Picks Disease and progressive isolated aphasia(CTv3)	F02.0	Dementia in Pick's disease
			F02.1	Dementia in Creutzfeldt-Jakob disease
			F02.2	Dementia in Huntington's disease
Eu023	Eu023	Dementia in Parkinson's disease	F02.3	Dementia in Parkinson's disease
			F02.8	Dementia in other specified diseases classified elsewhere

Table S1: Continued

Eu02y	X0034	Dementia in other diseases specified elsewhere (Read)/Frontotemporal dementia includes Pick's Disease and progressive isolated aphasia	G31	Other degenerative diseases of nervous system, not elsewhere classified
			G31.0	Frontotemporal dementia
Eu025 /F116	X003A	Lewy body dementia	G31.8	Other specified degenerative diseases of nervous system Grey-matter degeneration [Alpers] Lewy body(ies)(dementia)(disease) Subacute necrotizing encephalopathy [Leigh]
	XaKyY	Lewy body dementia		
Eu02z	XE1Z6	Unspecified dementia	F03	Unspecified dementia
			F05.1	Delirium superimposed on dementia
	X002w	Dementia		
	X00R2	Senile dementia		
E00..	E00..	Senile/presenile dementia		
1461	1461	History of dementia		
Eu107 Eu10711 E012 E0120	Xa25J	Alcoholic dementia	F10.7	Residual and late-onset psychotic disorder: Includes Alcoholic dementia NOS Chronic alcoholic brain syndrome Dementia and other milder forms of persisting impairment of cognitive functions

Anti-Dementia Medications

- Donepezil (Aricept® Aricept Eves®) Read Code: dy1
- Galantamine (Reminyl®, Reminyl® XL) Read Code: dy3...
- Rivastigmine (Exelon) Read Code: dy2...
- Memantine hydrochloride Read Code: dB1..

Table S2: Comparison of socio-demographic characteristics between sub-population (N=4668) and rest of EPIC-Norfolk cohort.

	Cohort		GP Sub-cohort		P-Value
	N=25 777*		N=4668		
Socio-demographic					
Mean (SD)					
Age at Baseline	59.9	(9.6)	56.2	(8.0)	<0.001
Age at dementia diagnosis	83.7	(6.6)	84.4	(6.6)	0.7
Sex, % women (n)	54.6	(14 063)	57.4	(2681)	<0.001
Education, % (n)					
No qualifications	39.8	(10 240)	33.1	(1546)	
O/ A level Standard	48.6	(12 510)	51.6	(2407)	<0.001
Graduate Level	11.6	(2992)	15.2	(711)	
Social Class, % (n)					
Professional	6.4	(1616)	8.5	(388)	
Managerial	35.2	(8833)	35.5	(1627)	
Skilled Non-Manual	16.7	(4199)	15.2	(697)	<0.001
Skilled Manual	23.7	(5948)	23.2	(1062)	
Semi-Skilled	14.1	(3545)	13.0	(597)	
Non-Skilled	3.8	(945)	4.6	(211)	
Dementia, % (N)	10.1	(2609)	4.4	(209)	<0.001

* Using full cohort as the sub population was based on this denominator and not 25,639 from baseline

Table S3: Summary of responses from 8 of the collaborating Practices providing GP data.

Response from Questionnaire sent to GP Practice	Number
Used both Read Code and Medication names in searches	7
Included additional dementia codes not listed in the 'Clean up exercise' protocol	4
Information available in records as coded and free text data (free text not provided for this study)	6 (0 Practices used free text alone)
Practices experiencing difficulty with using dementia Read Codes	6=No 1=Yes 1-No response
Does the Practice carry out In-house cognitive testing (Yes)	7
Reason for patient cognitive assessment/referral to memory clinic	7=Patient concern 6= GP Judgement 6= Opportunistic testing
How is a confirmed dementia diagnosis made	8= Following secondary referral 4= including GP judgement
How is information of a dementia diagnosis received by the Practice	7= Free text (As a letter) 1= Free text plus ICD code
How is information of a dementia diagnosis entered onto the local GP database	7= Read Code 1= (Free text, ICD and Read code)
Were all cases identified from searches already included on QOF* register	3=Yes 5=No
Was there a discrepancy between QOF* register and Read Code search	5=Yes 3=No

* Quality and Outcomes Framework

Dementia from HES records, death certificate or the MHDS was defined as any of the ICD-10 codes as listed in Supplementary Table S1.

References

- 1 Russell P, Banerjee S, Watt J, *et al.* Improving the identification of people with dementia in primary care: evaluation of the impact of primary care dementia coding guidance on identified prevalence. *BMJ Open* 2013;**3**:e004023. doi:10.1136/bmjopen-2013-004023
- 2 London Clinical Networks. "Coding clean-up" Exercise Guidance to GPs to improve dementia coding, and raise diagnosis rates: A step by step approach. London, UK:
- 3 Mukadam N, Livingston G, Rantell K, *et al.* Diagnostic rates and treatment of dementia before and after launch of a national dementia policy: An observational study using English national databases. *BMJ Open* 2014;**4**:1–8. doi:10.1136/bmjopen-2013-004119
- 4 Shohaimi S, Welch A, Bingham S, *et al.* Residential area deprivation predicts fruit and vegetable consumption independently of individual educational level and occupational social class: a cross sectional population study in the Norfolk cohort of the European Prospective Investigation into Canc. *J Epidemiol Community Health* 2004;**58**:686–91. doi:10.1136/jech.2003.008490