

BMJ Open Improving the identification of people with dementia in primary care: evaluation of the impact of primary care dementia coding guidance on identified prevalence

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ABSTRACT

Objective: Improving dementia care is a policy priority nationally and internationally; there is a 'diagnosis gap' with less than half of the cases of dementia ever diagnosed. The English Health Department's Quality and Outcomes Framework (QOF) encourages primary care recognition and recording of dementia. The codes for dementia are complex with the possibility of underidentification through miscoding. We developed guidance on coding of dementia; we report the impact of applying this to 'clean up' dementia coding and records at a practice level.

Design: The guidance had five elements: (1) identify Read Codes for dementia; (2) access QOF dementia register; (3) generate lists of patients who may have dementia; (4) compare search with QOF data and (5) review cases. In each practice, one general practitioner conducted the exercise. The number of dementia QOF registers before and after the exercise was recorded with the hours taken to complete the exercise.

Setting: London primary care.

Participants: 23 (85%) of 27 practices participated, covering 79 312 (19 562 over 65 s) participants.

Outcomes: The number on dementia QOF registers; time taken.

Results: The number of people with dementia on QOF registers increased from 1007 to 1139 ($\chi^2=8.17$, $p=0.004$), raising identification rates by 8.8%. It took 4.7 h per practice, on an average.

Conclusions: These data demonstrate the potential of a simple primary care coding exercise, requiring no specific training, to increase the dementia identification rate. An improvement of 8.8% between 2011 and 2012 is equivalent to that of the fourth most improved primary care trust in the UK. In absolute terms, if this effects were mirrored across the UK primary care, the number of cases with dementia identified would rise by over 70 000 from 364 329 to 434 488 raising the

Strengths and limitations of this study

- The general practitioners (GPs) who took part in this exercise were highly motivated and had been selected to participate in the National Health Service London dementia fellowship programme.
- Generalisability may be limited from these London practices to those in the rest of the UK.
- However, the coding systems used and GP information systems vary little so the demonstration that this exercise worked in practices across London may point its being applicable across the UK.
- We achieved a high participation rate and the practices covered a large population (179 312) over a wide and sociodemographically varied set of areas spread across 19 boroughs.
- The protocol generated was simple and required no training.

recognition rate from 46% to 54.8%. Implementing this exercise appears to be a simple and effective way to improve recognition rates in primary care.

BACKGROUND

Dementia is one of the most common and serious disorders in later life with a prevalence of 5% and an incidence of 2% per year in people over 65 years of age.^{1 2} In the UK, estimates suggest that there are 800 000 people with dementia currently.³ It causes irreversible decline in global intellectual, social and physical functioning. Abnormalities in behaviour, insight and judgement are part of the disorder, as are neuropsychiatric symptoms such as psychosis, anxiety and depression. The economic

cost of caring for people with dementia is immense. In the UK, the costs of dementia are around £17 billion/year,³ with some suggesting this as more than stroke, heart disease and cancer.⁴ More importantly, the negative impacts of dementia on those with the disorder, in terms of deteriorating function, and on carers^{5 6} are profound. There are 35 million people with dementia worldwide and this costs \$600 billion/year, with these numbers set to double and the costs to at least triple in the next 20 years.^{7 8}

The need to improve care for people with dementia is a policy priority nationally and internationally.^{9–12} One common finding in analyses of health systems with respect to dementia is that there is a ‘diagnosis gap’ in dementia with less than a half of those with dementia ever attracting a diagnosis of dementia. Also, such diagnosis and contact often occur late in the illness and/or in crisis when opportunities for harm prevention and maximisation of quality of life have passed. A common element of health strategies to improve the quality of care of people with dementia is the injunction that diagnosis rates should be increased and that diagnosis should be ‘early’ or ‘timely’.

Part of the Department for Health for England’s response to this has been to encourage primary care recognition and recording of dementia through its Quality and Outcomes Framework (QOF).¹³ This is designed to incentivise, via payment, primary care services to improve the quality of care by standardising improvements in the delivery of primary medical services. The relevant indicators for 2013/2014 include:

DEM001 The contractor establishes and maintains a register of patients diagnosed with dementia.

The number of people with dementia identified in these registers compared with projected numbers from the local age and gender structure has been used as a marker of progress against the goals of the National Dementia Strategy using a commissioned dementia prevalence calculator.¹⁴ Using this methodology, figures from the Alzheimer’s Society suggest that diagnosis rates in Britain range from 32% in the East Riding of Yorkshire to 76% in Belfast.¹⁵

These dementia registers rely on how dementia is coded in primary care record systems. This is generally via Read Codes which are a coded thesaurus of clinical terms that has been used within primary care in the National Health Service (NHS) since 1985. The codes available for dementia are complex with the possibility of underidentification through miscoding. NHS London therefore developed guidance on the coding of dementia (Web appendix 1). In this paper, we report the impact of applying this guidance in a sample of general practitioner (GP) practices across London to investigate whether it is possible to raise diagnosis rates through undertaking an exercise to ‘clean up’ dementia coding and records at a practice level.

METHOD

A coding exercise protocol was developed to enable GPs to conduct a review of practice records and to recode cases where needed. This was developed by PR and SB iteratively with key stakeholders, facilitated by NHS London co-ordinated by JW. The protocol is presented in full in Web appendix table 1. This consisted of a simple five-point process.

- Step 1: Identify commonly used Read Codes for dementia/memory concerns
- Step 2: Obtain practice’s QOF dementia register
- Step 3: Run searches to generate lists of patients who may have dementia
- Step 4: Compare search results with QOF dementia register
- Step 5: Discuss with patients for further review

Participating practices were drawn from boroughs across London which had a GP on the 2012/13 NHS London GP Dementia Fellowship Programme. The exercise was completed by the GP on the programme in each practice as set out in Web appendix table 1. The number of patients identified with dementia in the practice QOF registers before and after the exercise was recorded as were the hours taken to complete the exercise.

RESULTS

Sample

Twenty-three (85%) of the 27 practices available participated. These came from 19 boroughs across London. The participating practices had a practice population of 179 312 with 19 562 (10.9%) patients over the age of 65. The mean practice size was 8296 (range 2543–16 700). In terms of representativeness of the sample, this proportion over 65 years was similar to the overall percentage for London (11.2%); the London rate is lower than that for the UK as a whole (16.9%).

Impact of the intervention

The number of people in the practices’ dementia QOF registers before the intervention was 1007; after the intervention there were 1139 cases on the registers (practice population 179 312 with 19 562 aged 65+). This was a statistically significant increase ($\chi^2=8.17$, $p=0.004$). The mean number of people in the practices’ dementia QOF registers before the intervention was 44 (range 0–232, SD 49). After the intervention there was an average of 50 cases on the registers (range 0–248, SD 54); this was a statistically significant difference between those means ($t=3.52$; $p<0.001$). Taking the numbers aged 65+ in each practice as the denominator, this represents an identified prevalence of 5.1% before the intervention and 5.8% after. Using the most recent DH estimates,¹⁴ the expected number of people with dementia in London is 69 849 which equates to a prevalence of 8.11% of those aged 65+. We used this to calculate the identification rate before and after the intervention. After the intervention, 71.8% of cases of dementia were

identified compared with 63% before intervention. The effect of the intervention was therefore to increase the rate of identification of dementia in this sample by 8.8%.

Cost of the intervention

The only cost of the intervention was the person time spent on the exercise which took an average of 4.7 h per practice.

DISCUSSION

The data presented here demonstrate the potential of a simple primary care coding exercise, requiring no specific training, to increase the rate of identification of cases of dementia. In this sample of GP practices in London, an 8.8% improvement was achieved at a cost of an average 4.7 h of GP time.

Size of effect

We need to consider the meaning of the 8.8% increase observed. In their recent analysis of identification rates from QOF registers across the UK,¹⁵ the Alzheimer's Society calculated for each Primary Care Trust (PCT) area (the forerunners to current Clinical Commissioning Groups (CCGs)) identification rates in the same way that we have here. They did this for 2011 and 2012 and calculated changes in numbers and rank between 2012 and 2011. In rank terms, for a PCT, an improvement of 8.8% between 2011 and 2012 would have resulted in that PCT being the fourth most improved PCT in the UK (displacing Torbay that achieved an 8.2% improvement). In terms of ranking, an improvement of 8.8% would have moved a PCT up to an indicative 68 places (of 178). In absolute terms, if this were implemented across the UK primary care with the same aggregate effect, the number of cases with dementia identified in QOF registers would rise by over 70 000 from 364 329 to 434 488, raising the recognition rate from 46% to 54.8%.

Reasons for coding error

Implementing this exercise appears to be a simple and effective way to improve recognition rates in primary care. Completing the exercise also sheds some light on the reasons for the current coding errors. Part of this may be a wish to avoid labelling patients as having dementia on the QOF register unless there is a high level of certainty as to the diagnosis. This is an understandable and reasonable concern, as there is a stigma associated with the diagnosis, and professional attitudes to and confidence in the management of dementia may play a role in perceived under-recognition. However, all the cases reassigned in this exercise were those with an established dementia. The issues seemed more a function of computer and coding systems. This points to the potential value of this exercise. Ninety-eight per cent of London practices use Egton Medical Information Systems (EMIS) or Vision systems; these require coding by V2-5byte Read Codes. In this

system, there are a large number of potential dementia-related Read Codes that might be used and these are not presented in a way that is user friendly (Web appendix 1). In this exercise, we sought to address this by operationalising how these codes should be used. Equally, the letters received by GPs from secondary care services where diagnoses may have been made were often not clear in terms of diagnosis and diagnostic category. Letters from psychiatric services were often long with the diagnosis hidden in the text. We also found cases where the first assessment letter referred to 'probable dementia' but where the definitive diagnosis in a letter 3–6 months later had not led to the coding being brought up to date. The use of multiple systems and unfamiliar terminologies by secondary care leads to confusion and lack of clarity in coding within primary care. The simple expedient of all secondary care clearly stating the International Classification of Diseases (ICD) 10 codes or the most appropriate Read code to use would address this coding problem.

Limitations

This is a simple pragmatic study and the limitations of this exercise and the data presented here need to be considered. This was not a random sample of practices or of GPs. The GPs who took part in this exercise were highly motivated and had been selected to participate in the NHS London dementia fellowship programme. They were therefore interested in dementia and also built skills during the programme within which the exercise was completed. The main likely impact of this may have been to enable them to complete the exercise more quickly than the average GP. However, even if the exercise took twice the time, this would mean that it could be achieved in a single day. The generalisability of the practices within which the exercise was completed also needs to be considered. All were group practices and they were similar to the rest of London in terms of age structure; however, the practices studied had a higher than average recognition rate before the exercise (63%) compared with the UK as a whole (46%). This may reflect the interests of the participating GPs and their effect on coding in those practices. This is of interest because this suggests that we were intervening in practice systems that may have been more optimised than others might be. It is quite possible that in less optimised systems there might be greater levels of coding error and so an even greater effect might be achieved. As an estimate of effect, our results might therefore be considered conservative. There will be differences between London practices and those in the rest of the UK as evidenced by the difference in age structure in London compared with the UK as a whole. However, the coding systems used and GP information systems vary less, and so the demonstration that this exercise worked in practices across London may point its being applicable across the UK. Different countries have different systems and it is likely that the detail of the approach

here will only apply to the UK; however, the general issue of clarity in coding is likely to be of importance internationally. There are strengths in the approach used. We achieved a high participation rate and the practices covered a large population (179 312) over a wide and sociodemographically varied set of areas spread across 19 boroughs. Also, the protocol generated was simple and required no training. The data here represent a test of the feasibility of conducting the exercise and of the content of the protocol.

CONCLUSIONS

It is important to be clear that this coding exercise would form only a part of the comprehensive whole system effort to improve dementia care and to lift diagnosis rates through initiatives such as education and training, memory service commissioning, and service improvement.¹⁶ However, the results presented here suggest that completing this exercise could provide a simple, cheap and useful first step to improve accuracy of records. More accurate information can help to improve the management of patients and also help to close the diagnosis gap.¹¹ In terms of next steps, evaluations of the effect of coding exercise in a more representative sample of practices nationwide would be of use. But equally, given its simplicity and low cost, it may be that practices and CCGs would wish to implement this without needing further evaluation other than auditing local effects. In this paper, we have provided all the materials needed to carry out the exercise.

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The National Health Service London coding guidance and exercise are available on the South West Dementia Partnerships website at: <http://www.dementiapartnerships.org.uk/diagnosis/resource-pack/9-coding/>

Contributors All authors were involved in the design and conduct of the project; all but JW and SB carried out the exercise and collected the data. All participated in the editing of the paper and all agreed to the final content. PR and SB generated the coding protocol. Analyses were carried out by SB who also wrote the first draft of the paper. SB is the guarantor.

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Competing interests SB has received consultancy fees, speakers' fees, research funding or educational support to attend conferences from pharmaceutical companies involved in the manufacture of antidepressants and antidementia drugs, and has been employed by the Department of Health for England. JW has been employed by National Health Service London.

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WEB APPENDIX 1 – LONDON DEMENTIA CODING GUIDANCE

Guidance on Dementia Coding



What is the big issue for London GPs in coding dementia?

There is a dementia diagnosis gap of 52% in London, which means that only 48% of those who we would expect to have dementia, based on population prevalence rates, are recorded on GP practice dementia registers¹. We believe one of the reasons behind this apparently low diagnosis rate is a lack of accurate coding due to there being confusion with the available codes. This note for GPs contains guidance to help with this.

Why is it so important to diagnose and accurately code dementia?

1. It means the patient's care can be planned, managed and monitored, so that they can be signposted to supportive services and prescribed appropriate medication.
2. Diagnosis gives power to the patient and their families, as it brings clarity in terms of what is happening to them, and provides them with the ability to make choices themselves (National Dementia Strategy, 2009).
3. The coding of dementia and putting the patient on the dementia register means we can develop an accurate picture of London dementia rates to inform commissioning of high quality, cost effective services in response.
4. It means that GPs can see their own practice performance rise, and give patients confidence as they can see the identification rates on www.myhealthlondon.nhs.uk

Making dementia coding simple

The coding of dementia can be less than straightforward, so a team of GPs working to improve dementia care in London, with support from specialist experts, has put together this GP dementia coding guideline.

Guideline

1. We propose the use of four codes in primary care, which are listed below.
2. If the specific type of dementia is unknown, for whatever reason, please use the code **Eu02z** "Unspecified dementia". This can always be changed later when more information is available. Please do not use 1461.00 "h/o dementia", 28E.00 "cognitive decline" or similar codes for this purpose – these do not allow aggregation.
3. Where some diagnostic data are available the codes **Eu00.** can be used for Alzheimer's disease, **Eu002** for mixed dementia, and **Eu01.** for vascular dementia. All others can be given **Eu02z**.
4. A full list dementia codes can be found below. This matches ICD10 codes to recognised general practice dementia READ codes. Where detailed information on subtype of dementia is available, then these can be used.

The main codes which General Practitioners should use to code for dementia in primary care are:

ICD		Read
F00	Dementia in Alzheimer's disease	Eu00.
F00.2	Dementia in Alzheimer's disease, atypical or mixed type ("Mixed Dementia")	Eu002
F01	Vascular dementia	Eu01.
F03	Unspecified dementia	Eu02z

¹ QOF data, 2010/11

APPENDIX

ICD10		READ	ICD10		READ
F00	Dementia in Alzheimer's disease	Eu00	F05.1	Delirium superimposed on dementia Senile dementia with delirium	Eu041 E003
F00.0	Dementia in Alzheimer's disease with early onset	Eu000	F05.9	Delirium, unspecified	Eu04z
F00.1	Dementia in Alzheimer's disease with late onset	Eu001	F06.0	Organic hallucinosis Other senile and presenile organic psychoses Senile or presenile psychoses	Eu050 E00y E00z
F00.2	Dementia in Alzheimer's disease, atypical or mixed type	Eu002	F06.7	Mild cognitive disorder	Eu057
F00.9	Dementia in Alzheimer's disease, unspecified	Eu00z	F10.7	Residual and late onset psychotic disorder due to alcohol. Including: - Alcoholic dementia - Other alcoholic dementia - Chronic alcoholic brain syndrome	Eu107 Eu107.11 E012 E0120
F01	Vascular dementia Arteriosclerotic dementia	Eu01. E004	G30	Alzheimer's disease	F110.
F01.1	Multi-infarct dementia	Eu011	G30.8	Other Alzheimer's disease	
F01.2	Subcortical vascular dementia	Eu012	G30.9	Alzheimer's disease, unspecified	
F01.3	Mixed cortical and subcortical vascular dementia	Eu013	G30.0	Alzheimer's disease with early onset	F1100
F01.8	Other vascular dementia	Eu01y	G30.1	Alzheimer's disease with late onset	F1101
F01.9	Vascular dementia, unspecified Uncomplicated arteriosclerotic dementia Arteriosclerotic dementia with delirium Arteriosclerotic dementia with paranoia Arteriosclerotic dementia with depression Arteriosclerotic dementia NOS	Eu01z E0040 E0041 E0042 E0043 E004z	G31.0	Circumscribed brain atrophy Including: - Fronto-temporal dementia - Pick's disease - Progressive isolated aphasia	No Code F111.
F02	Dementia in other diseases classified elsewhere	Eu02	G31.1	Senile degeneration of the brain, not elsewhere classified	F112
F02.0	Dementia in Pick's disease	Eu020	G31.8	Other specified degenerative disease of the nervous system Including: - Grey matter degeneration - Lewy body disease - Lewy body dementia - Subacute necrotizing encephalopathy	F116 Eu025
F02.1	Dementia in Creutzfeldt-Jakob disease	Eu021			
F02.2	Dementia in Huntington's disease	Eu022			
F02.3	Dementia in Parkinson's disease	Eu023			
F02.4	Dementia in HIV disease	Eu024			
F02.8	Dementia in other disease classified elsewhere Dementia in conditions	Eu02y E041			
F03	Unspecified dementia Presenile dementia Uncomplicated presenile dementia Presenile dementia with delirium Presenile dementia with paranoia Presenile dementia with depression Presenile dementia NOS Uncomplicated senile dementia Senile dementia with depressive or paranoid features Senile dementia with paranoia Senile dementia with depression Senile dementia with depressive or paranoid features NOS	Eu02z E001. E0010 E0011 E0012 E0013 E001z E000 E002 E0020 E0021 E002z			

"Knowledge is power with respect to diagnosis, giving those affected and their families an understanding of what is happening and the ability to make choices themselves"

National Dementia Strategy, 2009

For a copy of the London Dementia Needs Assessment or any queries about dementia diagnosis and care, please get in touch with Jen.Watt@london.nhs.uk ; 020 7 932 2646

Table 1: Dementia coding exercise protocol

**Dementia “Coding Clean-up” Exercise:
Improving records of dementia diagnosis in your practice by more accurate coding**

Introduction - why is this important? Achieving early diagnosis of dementia is a major national priority, identified in the National Dementia Strategy and championed by the Government. Only 46% of those who we would expect to have dementia in London, based on population prevalence rates, are recorded on GP practice dementia registers¹. We believe one of the reasons behind this low diagnosis rate is problems in coding. We have previously developed guidance for GPs to support them to code dementia diagnoses accurately (see Appendix 4).

Aims The following exercise has been primarily designed to support GPs to identify problems in coding, which are contributing to low rates of dementia diagnosis on practice registers. It also provides a framework for GPs, to consider other patients who may have dementia, but are not yet diagnosed. It may also identify patients who have been lost to follow-up, which GPs can then address following local pathways.

Method

Step 1 – Identify commonly used Read codes for dementia/memory concerns At a practice meeting, discuss what codes GPs in your practice use when adding dementia or worries about memory to a patient’s problem list. Make a note of codes commonly used by your colleagues. Add any codes commonly used that are not already included on the list² in step 3 below.

Step 2 – Obtain Practice’s QOF dementia register Find the QOF dementia register for your practice³. Write the number of patients currently on the register, on the form in Appendix 3.

Step 3 – Run searches to generate lists of patients who may have dementia⁴ Run the following searches:

- | | | |
|----|--|-------------------|
| 1. | All those prescribed anti-dementia medication (See Appendix 2) | |
| 2. | “h/o dementia” | Read code 1461.00 |
| 3. | “Dementia monitoring” | Read code 66h..00 |
| 4. | “Dementia annual review” | Read code 6AB..00 |
| 5. | “Cognitive decline” | Read code 28E..00 |

¹ Dementia Prevalence Calculator, 2013

² These are the Read codes that were identified by the London pilot as being most commonly used. There is, however, variation from practice to practice, so it is important to have the discussion with colleagues, to identify codes your practice commonly uses. For example, other codes used in some practices in the pilot were: “Forgetful”, “Organic memory impairment”, “Short Term Memory Loss”

³ For EMIS and Vision, the codes that place patients on the QOF dementia register can be found in Appendix 1

⁴ It is possible that this part of the exercise can be done by your practice manager/ administrator

- | | |
|---|-------------------|
| 6. "Confusion" | Read code R009.00 |
| 7. "Memory loss Symptom" | Read code 1B1A. |
| 8. "Memory Impairment" | Read code Z7CEH |
| 9. "Short Term Memory Problems" | Read code Z7CF811 |
| 10. Any other codes identified by your colleagues in step 1 | |

NOTES: Searches 5 onwards are less specific. If you are from a large practice you may need to apply an age range (eg age over 65 only) to the search to make it manageable for step 4. If you work with care or nursing homes you may wish to also review the notes of these patients, as it is likely that many will have dementia.

** Please be aware that due to different GP computer operating systems you may not be able to find all of the listed read codes above. If you have been unable to find one particular code please just pass on.

Step 4 – Compare search results with QOF dementia register Compare the results of the searches with your practice QOF dementia register. Where discrepancies occur, review the notes to find out whether the patient has a diagnosis of dementia (in which case they can be coded as dementia using the codes in Appendix 1), whether they would benefit from an assessment, or whether they clearly do not have dementia.

Record the results on the form in Appendix 3. NOTE: If you find cases where dementia has been diagnosed but not coded, then it is best to date the diagnosis to the time it was made. This avoids QOF targets inappropriately requesting screening bloods etc.

Step 5 – Discuss patients for further review

At the next practice meeting discuss the list of patients you have identified who might benefit from a memory assessment and consider how best to offer this e.g. visit by usual doctor or letter inviting them to come in for a review.

Appendix 1 – Read codes

Dementia Read Codes
Dementia in disease EC (Eu02.%)
Senile / presenile organic psych (E00..%)
Vascular dementia (Eu01.%)
Drug-induced dementia (Eu02y1)
Other alcoholic dementia (E012.%)
Dementia in Alzheimer's disease (Eu00.%)
Dementia in conditions EC (E041.)
Delirium superimp dementia (Eu041)
Alzheimer's disease (F110.)
Pick's disease (F111.)
Senile degeneration of brain (F112.)
Lewy body disease (F116.)

Appendix 2 - List of anti-dementia medication

Anti-Dementia drugs
Donepezil (Aricept [®] , Aricept Evess [®])
Galantamine (Reminyl [®] , Reminyl [®] XL)
Rivastigmine (Exelon [®])
Memantine hydrochloride (Ebixa [®])

Appendix 3 – Results submission form

Please return to when completed

Dementia “Coding-clean up” Exercise

Practice Name:

General

Before start of exercise - number on QOF dementia register	
After exercise - number on QOF dementia register	
Number of patients who would benefit from assessment	

Detail

Please note, the numbers in the below table may not add up to totals entered in the table above, as there may be more than one coding issue identified per patient.

Note – the figures in these three columns should add up to the figure in the total column on the left					
Search	Total no of patients with this code	Number with this code, with confirmed dementia, who <u>were</u> on the QOF dementia register at the start of the exercise	Number with this code, with confirmed dementia , who <u>were not</u> on the QOF dementia register at the start of the exercise	Number with this code without confirmed dementia	Number with this code without confirmed dementia that would benefit from an assessment
Anti-dementia Drugs					
h/o dementia					
Dementia Monitoring					
Dementia Annual Review					
Cognitive Decline					
Confusion					
Memory loss symptom					
Memory Impairment					
Short term memory problems					
Local codes (please specify)					
i					
ii					
iii					
iv					