DEMENTIA SERVICES
CASE STUDY

Improving accuracy of the GP practice dementia register

Summary
In one GP Practice in South Manchester, a simple, systematic audit of the coding on an EMIS general practice dementia register increased the number of registrations from 50 to 74 without clinical intervention.

Context
Accurately coding patients with dementia enables primary care teams to provide better clinical care including dementia reviews, more coordinated care and identification of carers who may require support. Having accurate diagnosis numbers assists the GP practice and community teams, the clinical commissioning group and health and wellbeing board to understand the demand for dementia service provision and funding.

What we did and how it worked
Initially our team in Manchester studied the findings of Dr Paul Russell and Professor Sube Banerjee within London, who had reported on work to review and refine clinical coding on the dementia register. Dr Russell had searched his practice list for codes that might indicate a diagnosis of dementia. He reviewed the patient records, and where possible, coded dementia patients appropriately. In this way he had increased the register from 95 to 125 patients.

As a baseline and to assess the success of our project in South Manchester we calculated the predicted prevalence for our patient demographics. According to the Alzheimer’s Society, using a variety of sources, the prevalence of dementia in the United Kingdom is as follows:
• 1:1400 age 40-64 and we have 4150 patients = 3
• 1:100 age 65-69 and we have 430 patients = 4
• 1:25 age 70-79 and we have 569 patients = 23
• 1:6 of those over 80 and we have 411 patients = 68.

This gave us an expected practice prevalence of 98 people.

It was noted that all of the patients on our existing register had a dementia review carried out by a doctor within the previous 12 months.

Sequential searches of our registered patients were undertaken, comparing them to the existing EMIS system dementia register and adding patients to the register where appropriate after each search. The reviews involved no clinical contact; only assessing information recorded in the patient’s record.

The searches were as follows:
• Memory loss, (1B1A, 1B1A-2)
• EMIS Dementia codes, (EMISNQDD2, EMISNQDV1, EMISNQDD1, EMISNQDD3)
• Confusion, (2481-1, R009)
• Cognitive decline, (28E)
• Dementia Review, (6AB, EMISNQDE1)
• History Of Dementia, (1461)
• Dementia drugs prescribed, (Donepezil, galantamine, memantine, rivastigmine)

At each stage the register was examined against the search results to look for those not correctly coded.

Results
Prior to carrying out the exercise the dementia register had 50 patients.

Searching for memory loss (codes 1B1A, 1B1A-2) found 90 patients. 21 were on our dementia register. 15 had a diagnosis of dementia in the records not coded or incorrectly coded. These were added to the dementia register. 13 other people had been referred to memory clinic and awaiting investigation or formal diagnosis.
Two had been seen with memory loss and investigation had been offered, but refused. Three had a code of memory loss and had not been investigated for dementia, but it was felt they should be followed up to assess them clinically. The remaining 36 had a code of memory loss related to other conditions.

Adding the 15 brought the dementia register to 65. Two of the patients found on the search for memory loss symptoms were coded as dementia, but the codes were specific to the EMIS operating system (codes EMISNQDD2, EMISNQDV1, EMISNQDD1, EMISNQDD3). These codes exist for a number of conditions and are not picked up and added to the register. A search for others with EMIS codes brought up a list of six patients, two of which were exclusively coded with an EMIS code and these two were added to the dementia register.

The overall register increased to 67. The search for confusion codes (2481-1, R009) brought up a further 14 patients. Of these, six were on the dementia register. Of the other eight, two could be coded directly and were added to the dementia register. One was awaiting diagnosis having been referred to memory clinic.

This increased the total to 69.

The search for cognitive decline (28E) added no new patients to the register although three patients had been added from the previous searches.

51 patients had been coded as having had a dementia review in the previous year (codes 6AB, EMISNQDE1). This was all of our original register plus one who was not on the register. The additional one was added directly.

This brought the total register to 70.

Searching for history of dementia (code 1461) identified eight patients. All of these patients were on the register. Three of them had been added to the register following earlier searches so no new patients were added from this search.

The search for dementia drugs (donepezil, galantamine, memantine, rivastigmine) brought up 40 patients. Four of these patients were not included on the register. All could be coded for dementia and four were added.
This increased the register to a total of 74, an overall increase of 24 patients resulting from all of the searches.

The process of reviewing our register based on coding increased our recorded patients with dementia from initially 51% (50 patients) of the predicted prevalence (98 patients) to 75% (74 patients). If we include the three patients needing investigation, the two who declined investigation and the 13 referred to memory clinic, this would rise to 94% (92 patients) of the predicted prevalence. It is likely there are further patients who have not had any of the searched for codes recorded, or have not yet come to the attention of medical services. This suggests the estimated prevalence is accurate.

**Learning**

The process raised a concern that this demonstrated a problem with coding of patients with significant diagnoses. As a long-standing training practice, computer coding was used as early as 1986. A deanery pre-requisite for having trainee doctors is that patient records are accurately summarised and the practice has always complied. Trainee doctors may be less likely to accurately code information from letters for a variety of reasons, including lack of familiarity with the patients, computer system or importance of coding. This may have a bearing on the problem. It is interesting that Dr Russell demonstrated a similar problem in his work. Without further study it is impossible to be sure if this problem is unique to dementia, but a search for diabetic drugs did not reveal the same problems with patients not being on the diabetic register.

Are there factors making the accurate coding of dementia less likely? The diagnosis of Alzheimer’s dementia at least is entirely clinical and one of exclusion. Doctors tend to respond well when a tangible and reproducible result demonstrates diagnosis. The GP is currently divorced from the process of diagnosis and treatment of dementia. In most areas specialist teams finalise diagnosis and treatment. This may lead to a feeling of reduced responsibility and be reflected in poor coding.

How necessary is specialist diagnosis? Looking at the patients awaiting memory clinic it was clear that most, if not all, could be diagnosed in primary care with the appropriate investigations and clinical support.

The long delay between referral and diagnosis at memory clinic does not help accurate record-keeping. There is a risk of loss of continuity. Assumptions may be made regarding the patient’s diagnosis, leading to a failure to check and code when information does arrive from specialist services.

When communication is received it is often as part of a lengthy assessment for several patients. Where coding was absent the diagnosis was described as ‘probable’ or ‘most likely’ perhaps leading to reluctance to code until the diagnosis is finalised. It is important to note again that all of the patients coded correctly were reviewed by a doctor for their dementia in the previous year. Only one of those not coded had been reviewed for dementia. The system of disease registers does encourage and facilitate assessment for chronic diseases and is likely to improve patient care.

It is clear that new approaches to dementia will be required as the number of people with the condition increases. It would seem logical to base solutions where possible in Primary Care for this vulnerable group.

**Recommendations**

- Training grade doctors should not deal with routine mail in general practice until nearing the end of their specialist training.
- Patients should be coded as “Query Dementia”. By coding as Query Dementia at the outset the patient would be added to the dementia register and it would reduce the chance of the patient being lost to follow up. If the diagnosis was not confirmed the code would be picked up through the Quality Outcome Framework work and corrected.
• The appropriate codes for dementia should be agreed between the hospital and general practice.
• Significant diagnosis notification and Read code highlighted on letters from the hospital. If letters containing a new diagnosis have this clearly indicated in a separate section and contained the agreed Read code it is likely coding would improve.
• Moving towards general practitioner diagnosis to speed up diagnosis and treatment would help engage both patients and family doctors in the process. This may be facilitated by psychiatry support in local surgeries and may still comply with current NICE guidance.

**Read codes used in primary care**

<table>
<thead>
<tr>
<th>Code</th>
<th>Condition</th>
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<tbody>
<tr>
<td>Eu01</td>
<td>Vascular dementia</td>
</tr>
<tr>
<td>F110</td>
<td>Alzheimer’s disease</td>
</tr>
<tr>
<td>Eu02</td>
<td>Dementia in Alzheimer’s disease, a typical or mixed type</td>
</tr>
<tr>
<td>F116</td>
<td>Lewy body dementia</td>
</tr>
<tr>
<td>Eu02z</td>
<td>Unspecified dementia</td>
</tr>
<tr>
<td>28E0</td>
<td>Mild cognitive Impairment</td>
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