

Actions to increase diagnosis rates by 2015

Introduction

In 2012 the Department of Health announced an ambition for the NHS that in 2015 two thirds of people in our populations with dementia would have received an assessment and diagnosis. This resulted from annual data showing that in many parts of the UK fewer than half of people with dementia had received a diagnosis, and thereby were likely to be missing out on local services designed for people who had been diagnosed.

The data is normally expressed as “diagnosis rate”, expressed as a percentage and calculated as the number of people appearing on GP Quality & Outcome Framework Dementia Registers (numerator) divided by an estimate of the number of people in the same population who ought to have dementia (denominator), multiplied by 100. Thus the **national ambition for 2015 is a diagnosis rate of 66%**.

Early figures for 2013-14 suggest that many Clinical Commissioning Group areas still have diagnosis rates well below 66%, and some still have rates well below 50%, with annual increases of the order of only 6%. Therefore extra work needs to be done in many areas of the UK to achieve the national ambition for 2015.

Data limitations

Although there seems little doubt that in many parts of the UK people with dementia are still living in communities without having had a proper assessment and diagnosis, there are difficulties with using diagnosis rates as a measure of quality of dementia care in the UK.

Limitations include the following:

- Many people who have received a formal diagnosis may not appear on GP QOF registers simply through the lack of the correct Read Code in their clinical record. These people may still have access to post-diagnosis services and supports.
- There are problems with how the denominator is calculated. This applies age and sex band prevalence estimates to population figures for a given geographical area. Population figures are usually projections by the Office of National Statistics using the latest National Census results. However:
 - The age and sex band prevalence estimates were set several years ago by a Delphi Consensus of dementia experts and based on a limited amount of published research of variable quality available at the time.
 - Recent international research suggests that the estimated prevalence figures which these age and sex bands produce may be an overestimate by as much as 24% (The Lancet Online, 13th July 2013: [http://dx.doi.org/10.1016/S0140-6736\(13\)61570-6](http://dx.doi.org/10.1016/S0140-6736(13)61570-6)), resulting in diagnosis rates being lower than they should be and raising the potential that 66% might in fact be impossible to achieve.
 - An estimated prevalence figure designed for the whole population may not be accurate for a smaller population because of the effect of pockets of high or low prevalence related to the number of local care homes (within which prevalence is

expected to be higher than in the community) or the level of local deprivation. This issue has partly been addressed with the development of the Dementia Prevalence Calculator which includes an adjustment for the number of care home beds in a given population.

Methods to improve diagnosis rates

The following methods have been shown to be effective at increasing diagnosis rates in populations in the UK, and are drawn either from published research or from specific examples from NHS Scotland (where diagnosis rates rose dramatically between 2010 and 2012) and Clinical Commissioning Groups in England who have demonstrated similarly good increases or current diagnosis rates (including NHS Portsmouth CCG whose diagnosis rate is currently 69% and the highest of all CCGs in the South of England).

1. Commission local **post-diagnosis support services** for people with dementia and their carers to provide information, support, signposting and advocacy from the point of diagnosis to end of life. This will help to avoid people falling into a 'care vacuum' after diagnosis and address one of the barriers to diagnosis: that a diagnosis offers no benefit to the patient or carer (particularly if acetylcholinesterase inhibitors are not indicated). It will also improve outcomes for people with dementia and their carers, reduce carer stress and potentially delay the need for permanent care home placement (particularly if a case management approach is utilized with close primary care and community services engagement).
2. Support the development and ongoing operation of **community support systems** for people with dementia and their carers by third sector organisations, including initiatives such as Memory Cafes, Dementia Friendly Communities, Dementia Friends and Befriending Services.
3. Ensure that **GP QOF registers** are an accurate record of all people in a population with a diagnosis. This may be undertaken using a variety of methods but combining all of them is likely to be most successful. Methods used with success are:
 - 3.1. Checking that all patients prescribed **Acetylcholinesterase inhibitor** medication appear on the GP QOF register, and if they do not adding a Read Code to their records so that they do (NHS Somerset CCG identified over 300 patients using this method alone);
 - 3.2. Searching GP clinical computer systems for **dementia-related Read Codes**, checking the records of patients identified and if they have evidence of having been diagnosed with dementia adding a suitable Read Code to their records so they then appear on the GP QOF register (see Appendix 1 and BMJ Open 2013;3:e004023);
 - 3.3. Ensuring that correspondence from Memory Clinics or Community Mental Health Teams (CMHT) to GPs informing them that a diagnosis of dementia has been made **includes a recommended Read Code** for the GP to add to that patient's record so that they appear on the QOF register;
 - 3.4. Comparing **Memory Clinic and CMHT lists** identifying who they have diagnosed with dementia in the past few years with the GP QOF register and adding a suitable Read Code to the records of patients who are missing;

- 3.5. Providing peer-delivered in-house (NHS Devon & Torbay PCTs during 2011-12, resulting in a quadrupling of referrals to Memory Clinic by GPs) or protected time **GP dementia awareness-raising** events for all GPs in the area (NHS Portsmouth CCG) in order to:
 - 3.5.1. Challenge the well-researched barriers to diagnosis which continue to be held by a number of GPs;
 - 3.5.2. Highlight the benefits of diagnosis for the patient;
 - 3.5.3. Highlight the benefits of an accurate QOF register for the GP (including financial: see example in Appendix 2);
 - 3.5.4. Publicise the range of local post-diagnosis services and supports for people with dementia and their carers, and simple ways for GPs and their staff to help their patients with dementia.
- 3.6. Ensure that work to improve the accuracy of GP QOF registers is **linked to other current GP initiatives** including:
 - 3.6.1. The national primary care enhanced service for dementia;
 - 3.6.2. The national hospital CQUIN for dementia;
 - 3.6.3. The new primary care Avoiding Unplanned Admissions enhanced service and Over-75s contractual requirement;
 - 3.6.4. Frail Elderly care pathways, virtual wards, or Community Hub arrangements aimed at bringing care back into the community and reducing the need for hospital admission;
 - 3.6.5. Improvements to End of Life Advance Care Planning processes and documentation, including application of the Mental Capacity Act 2005 and Best Interest Decision-making following a recent House of Lords review and court judgements.
4. Commission a project to identify care home residents without a diagnosis of dementia but who might have dementia, assess them and request that their usual GP adds them to the dementia QOF register if dementia is diagnosed (now operating in NHS Gloucestershire, NEWDevon, Somerset, South Devon & Torbay and Wiltshire CCGs). The benefits of this approach are that:
 - 4.1. The prevalence of dementia in care homes is estimated at around 60-70%, much higher than the general community, which makes the chance of finding greater numbers missing from QOF registers is likely to be good;
 - 4.2. The care home residents' registered GPs need not be expected to undertake the assessment as it could reasonably be done by a member of the local CMHT or a local lead GP for dementia;
 - 4.3. Dementia is a stated priority area for CCGs and Health & Wellbeing Boards and because the project is working in care homes but closely liaising with GPs there is clear integrated working and suitability for funding allocation from the local Better Care Fund;
 - 4.4. The benefits of this project could be enhanced through links with care home CMHT in-reach services and social care dementia education for care home staff.

5. Commission a Local Enhanced Service, or Service Level Agreement, with local GPs to support **greater primary care involvement in the diagnostic process** including where acceptable to make and record a diagnosis without referral to the local specialist Memory Clinic. Successful examples of such an arrangement in the South West have included the provision of specialist out-reach memory nurses (usually CMHT Community Psychiatric Nurses or Occupational Therapists) with strong links to named GP Surgeries who provide expert support to the diagnostic process in primary care (now in operation in NHS Bristol and South Gloucestershire CCGs). Please note:
 - 5.1. Care must be taken to avoid overlap of service specification with the existing national enhanced service for dementia;
 - 5.2. Such an arrangement can enhance the effectiveness of the national hospital CQUIN for dementia without placing undue demand pressures on the local Memory Clinic;
 - 5.3. Primary care involvement in assessment and diagnosis will release specialist resources to allow improvements to other parts of the dementia care pathway such as the management of behavioural problems in the community.
6. Commission a specialist **care home in-reach service**, such as NHS Portsmouth's Mental Health Care Home Matrons, who sit alongside physical health community services and can deliver:
 - 6.1. Assessment of care home residents who are likely to have dementia but lack a diagnosis;
 - 6.2. Targeted education of care home staff, for example around specific situations occurring with their residents;
 - 6.3. Mental health expertise into local virtual ward or community case management arrangements involving other community services, GPs and community geriatricians.
7. Agree a **community services provider CQUIN** for district nursing teams to identify older people still living in their own homes who might be at risk of having dementia by virtue of their need for community nursing support and in many cases domiciliary social care support.
8. Review and enhance existing acute and community hospital specialist **mental health liaison services** to support implementation of the national CQUIN, assist with inpatient management and earlier discharge planning, and liaise with GP and CMHT at discharge regarding diagnosis (if made during inpatient stay) or appropriate further assessment.

Nationally, efforts to improve the accuracy of dementia prevalence estimates (the denominator in calculating diagnosis rates) in light of recent published research offers the potential to ensure that diagnosis rates are both a more reliable indicator of dementia care performance within the NHS but also that diagnosis rates for smaller populations can be compared more reliably with each other than is currently the case. To this end, the Department of Health has commissioned the Alzheimer's Society to undertake a **refresh of their original Delphi Consensus estimated prevalence age and sex bands** which should be available in the autumn of 2014 prior to the national aspiration deadline of 2015.

Evaluation

It is, of course, vital that CCGs, H&WBBs and other organisations undertaking projects designed to improve diagnosis rates for dementia in their populations are properly evaluated to understand their impact. Outputs for such evaluations should include as a minimum:

- a. The number of people who have been added to GP QOF registers as a direct result of the project concerned;
- b. The change in diagnosis rate for the population concerned from before the start of the project to after its completion.

Given the simple nature of these outputs such evaluation may easily be done in-house but involvement of the local Academic Health Science Network or Strategic Clinical Network offers the opportunity to pool outputs from different organisations and share best practice. Such evaluation may then also be linked with other regional dementia work streams so that the benefit to each individual person of receiving a diagnosis is maximized as well as the aspiration for 2015 being reached.

Conclusions

Local statutory organisations whose current dementia diagnosis rate's annual growth trajectory looks likely to fall short of the 66% aspiration for 2015 may wish to consider **a variety of different targeted actions** which have delivered increases in diagnosis rates in other parts of the UK.

Some of these actions are simple and likely to deliver rises in a relatively short period of time and at low cost (options 3 & 4 above); some will require greater investment and are likely to show impact on diagnosis rates in the medium term but may be for a fixed term only (options 5, 6 & 7); and some will require more long-term commissioning or support and take several years to impact on diagnosis rates as their benefits embed in the local community (options 1, 2 & 8). Statutory organisations may therefore wish to consider several options that are mutually enhancing and potentially offer a compound effect on diagnosis rates (e.g. options 1, 2, 6, 7 & 8 as done by NHS Portsmouth in association with their local older person's mental health provider Solent NHS Trust).

The importance of taking some action cannot be understated: either this will lead to the CCG concerned reaching the national aspiration by next year where otherwise they might not have; or the CCG will be in a position to demonstrate targeted work towards the aspiration and to benefit people with dementia in their population should they still not achieve the aspiration but still increase their diagnosis rate towards it.

Dr Nick Cartmell, September 2014

Appendix 1

Dementia-related Read Codes used in primary care as part of a coding clean up protocol developed by Dr Paul Russell, GP and dementia lead for NHS Waltham CCG, and used by NHS London as part of the research project published in the BMJonline in June 2014.

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

A step by step approach

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

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

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
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 (e.g. 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.

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 2

UNDERSTANDING PREVALENCE - Dementia

Based on the latest prevalence figures & QoF payments

An important feature of the QoF is the establishment & maintenance of disease registers - the wording on most registers has changed in QoF 13/14 which will see you have to demonstrate how you maintain registers. Whilst it is recognized that these may not be 100% accurate, it is the responsibility of the practice to demonstrate the systems you have in place to maintain a high quality register. If you are not able to explain how you establish & maintain your registers, you could have register points deducted.

PRACTICE 1 – 10,000 patients Low prevalence, high point achievement	PRACTICE 2 – 10,000 patients High prevalence, less point achievement
Average £ per point = £227.02	Average £ per point = £227.02
Dementia National Prevalence = 0.5%	Dementia National Prevalence = 0.5%
Practice Prevalence = 0.3%	Practice prevalence = 0.7%
Dementia point value drops to £136.21	Dementia point value increases to £317.83
Dementia points achieved = 26 (maximum)	Dementia points achieved = 20
Total income for dementia = £3,541.46	Total income for dementia = £6,356.60

Income increase by adding 10 patients to the register	£1,180.50
Income increase by adding 20 patients to the register	£2,361.00
Income increase by adding 50 patients to the register	£5,902.51

This example is to be used for illustration purposes only, it is not based on data taken from a practice & uses the latest prevalence figures & QoF point value available.