NHS
Yorkshire and the Humber
Clinical Networks

Dementia Data Quality Toolkit - *updated*

Frequently asked questions

5th July 2017

1. What is the dementia data quality toolkit?

The dementia data quality toolkit incorporates system searches for *EMIS Web and SystmOne practices*. These will generate a list of patients who have a coded entry on the practice system that may be indicative of dementia but who do NOT have a corresponding dementia diagnosis code that includes the patient on the QOF dementia register.

For a full list of the codes included in the search, please see Appendix 1. A technical implementation guide is also available for each system (*HERE*) which gives instructions on how to join the organisational group to access these searches, how to import (where appropriate) and run the system searches and how to use the report generated.

2. What has changed in the latest version of the toolkit?

The original version of these searches included only those patients aged 60 years & over when the coded entry was made. *This has now been updated to include patients aged 45 years & over.*

3. Why are we doing this work?

Although there has been a marked increase in dementia diagnosis rates during the last five years, some CCGs have not yet reached the national ambition that at least two-thirds of people who are estimated to have dementia should have a diagnosis. For a summary of dementia diagnosis rates for CCGs and STP's across Yorkshire & Humber as at end of June 2017, click here.

Monthly rates at CCG level, STP level and numbers on GP practice dementia registers are now made available at: http://www.digital.nhs.uk/catalogue/PUB30029.

Even in those areas where the national ambition has been reached, there are still people living with dementia who have not yet had a formal diagnosis. Getting a formal diagnosis enables people with dementia and their families to access support, medication and therapeutic interventions. Previous work has shown that the data quality toolkit helps practices to identify those patients who are living with dementia but who are not currently on the practice dementia register.

4. How do I access the updated toolkit?

For SystmOne practices, the updated toolkit is available via a new organisational group which practices will need to join. Detailed instructions on how to do this are here. If you

previously joined the YHCS dementia group, you can leave this group as the resources on this site will not be updated (see instructions here).

EMISWeb practices will access the resources via the original organizational group (instructions here).

5. What benefit is this to patients?

National and local studies have shown that patients and carers want to know that they have dementia. A diagnosis can open doors to: access to timely medication; other forms of support including social, therapeutic and financial; the opportunity to discuss wishes and plan ahead; access specialist palliative care in a timely manner. A diagnosis also helps services to adapt care and communication to meet the needs of the individual and to provide relevant information for the patient and carer.

6. How do I find out what my GP practice dementia diagnosis rate is?

GP practice dementia diagnosis rates are no longer published by the national team as expected numbers at individual GP practice level are small, associated confidence intervals are wide and therefore the data is difficult to interpret at this level.

Data is being extracted on a monthly basis from general practice to identify the **number of patients** on each GP practice dementia register and these are available to view at: http://www.digital.nhs.uk/catalogue/PUB30029.

7. What happens for people who are in residential care who have advanced dementia?

It is expected that the majority of diagnoses will largely be recorded following patients being referred to memory services/ secondary care with suspected dementia or as an additional diagnosis when a patient is seen in secondary care.

However it is also important to include on the GP practice dementia register those patients where it is inappropriate or not possible to refer to a secondary care provider for a diagnosis. In this instance, the GP should make a diagnosis based on their clinical judgement and knowledge of the patient. The DiADeM (**Di**agnosis of **A**dvanced **De**mentia **M**andate) tool is available to support GPs and other healthcare practitioners to make a diagnosis of moderate to advanced dementia for people living within a residential care or nursing care setting. The tool is available to download as a printable document or app version from: https://diadem.code4health.org/.

7. Is there funding available to support this work?

QOF DEM indicator 001 is worth 5 points and requires that, “The contractor establishes and maintains a register of patients diagnosed with dementia.” Re-running the toolkit searches at regular time intervals (e.g. every 6 months) will help the practice to demonstrate that they are complying with the requirement to maintain their dementia register.

In addition, ***increasing the number of patients on the practice QOF dementia register will increase pay per QOF point.*** See worked example, Appendix 2.

8. What codes should be used to record dementia and other relevant diagnoses?

Diagnostic description	Read Code (e.g. EMIS systems)	CTv3 code (e.g. SystmOne)
Alzheimer's Disease ✞	Eu00.	F110.
Vascular dementia ✞✞	Eu01.	XE1XS
Mixed dementia	Eu002	Eu002
Dementia in Parkinson's disease	Eu023	Eu023
Unspecified dementia	Eu02z	XE1Z6
Lewy-body dementia	Eu025	XaKyY
Fronto-temporal dementia	Eu02y or Eu020 (Pick's Disease)	X0034
Residual & late onset psychotic disorder due to alcohol/ Alcoholic dementia	E012.	Xa25J

✞ Lower level codes can also be used i.e. e.g. Eu000-z Early, late, mixed and unspecified 4
✞✞ Lower level codes can also be used i.e. Eu010-z

If a patient is diagnosed with Mild Cognitive Impairment, the code to use is:
Read Code Eu057 or CTv3 code X00RS as appropriate for your GP practice system.

To record a diagnosis of delirium which is NOT superimposed on dementia, use Read Code F05.0 or CTv3 code Eu040 (where not superimposed on dementia). For delirium which IS superimposed on dementia, use Read Code F05.1 or CTv3 code Eu041.

9. How long will it take the practice to run and action the dementia data quality searches? And what work is needed?

The searches themselves will take less than a minute to run and this will generate a Work to Do list for the practice. For practices running these searches for the first time and who have not already carried out validation work on their dementia registers, it may take up to 4-5 hours of GP time to work through the list of patients generated.

For those practices who have run the toolkit previously, the generated list should be much shorter as it will exclude those patients who've previously been removed from the list by adding the code (Read Code 6A5, CTv3 code Xalpj) to indicate they've already been reviewed.

For the patients on the Work to Do list, there are 4 possible courses of action:

- The GP reviews the patient and the code picked up within the search and decides that this patient does not need further investigation. e.g. patient with a normal 6-CIT assessment within the last 18 months. The GP adds the code to remove the patient from the work to do list (Read Code 6A5, CTv3 code Xalpj).
- The GP reviews the patient record and identifies that the patient has been diagnosed but that no diagnosis code has been added e.g. correspondence from memory services indicates a diagnosis but this has not been coded appropriately. The GP adds the relevant diagnostic code to the patient's record (see list of codes, question 8) and the patient will automatically be removed from the work to do list.
- An on-screen review of the patient record indicates that the patient may have dementia but has not been formally diagnosed. A rapid review appointment with the most appropriate GP is arranged as soon as possible for onward referral to the memory service if appropriate.
- An on-screen review of the patient record indicates that the patient may have dementia but has not been formally diagnosed. The patient requires home visits to their care home due to their frailty levels. The GP or other healthcare practitioner visits the patient and identifies a high likelihood of advanced dementia. They use DiADeM to make a diagnosis and add the diagnosis of unspecified dementia (Read Code Eu02z or CTv3 code XE1Z6) to the patient's record. The patient will automatically be removed from the work to do list.

It is likely that the number of patients identified who need a clinical review will be relatively small.

10. I've got a really long list of patients – where do I start?

So far, the codes found to generate the most patients with a positive diagnosis are: medication codes, codes for referral to memory service, history of dementia and dementia review and for EMIS practices, any EMIS-specific codes.

Patients who have been prescribed Rivastigmine (e.g. for Parkinson's Disease dementia) may have been diagnosed by neurology services rather than the more usual memory services route and therefore a diagnosis of dementia may have been more likely to be overlooked by coders.

So patients who've been picked up with any of these codes are probably a good starting point.

11. By how much is this work likely to increase the practice diagnosis rate?

As part of the toolkit development work, the system searches were run in three very different GP practices in Bradford covering over 23000 patients and with starting diagnosis rates of 38.8% up to 76%. The most 'productive' audit was in the practice with the lowest starting diagnostic rate in which it increased the percentage diagnosis rate by 44%. However even in the practice with a starting diagnosis rate of 76% there was an increase in the number diagnosed of 6%.

Similar work has been carried out in a Manchester practice where 24 additional patients were added to the register from the GP reviewing the notes, increasing the diagnosis rate from 51% to 75%. An additional 16 patients were referred to the memory clinic for further investigation. **http://tinyurl.com/m255cvd**

Even in those practices with a relatively high starting diagnosis rate, using this approach has demonstrated an increase in rates e.g. in London, a group of 23 GP practices with an average starting diagnosis of 63% increased diagnosis rate to 72%.

11. If a diagnosis code is being added to the patient record retrospectively, how do I address the QOF requirement that bloods are done?

If, after reviewing a patient, you decide that a diagnosis of dementia has been missed then code the diagnosis and backdate the entry to the date when the diagnosis was made (if known) or the date that the code picked up in the system searches was entered. If the date of diagnosis is before 1st April 2014 then there is no need to complete blood tests as a requirement for QOF. If the date of diagnosis is after 1st April 2014 then blood tests should be checked in line with QOF requirements that bloods are recorded between 6 months before or after entering on to the register.

Bloods should be considered in all these patients and patients should only be exempted in those people in whom it would not be in their best interest or where it would be too distressing for the patient to obtain them. An exemption excludes patients from all aspects of the dementia QOF, including the 'Dementia Review' so the clinical reason for exemption should be fully recorded.

Appendix 1

The system searches will identify those patients who have at least one of the codes listed in the table below recorded in their notes, with the following additional criteria:

- Patients age at event is 60 or over (other than for Referral to Psychiatry for the Elderly Mentally Ill and Memory Services which have age range of 45 years)
- Exclude any entry from over 5 years ago
- Exclude any entry for Referral to Memory Clinic that has been made in the last 4 months.
- Exclude any patient who has had 'Memory Recall Normal/Memory Function Normal/Mild Cognitive Impairment/Mild Cognitive Disorder' added in the last 12 months
- Exclude anybody already on the Dementia register.
- The drug searches include any drug in the 'Dementia' action group.
- Excludes patients previously picked up and reviewed using the toolkit within last 6 months

Description	Read Code	CTv3 code
H/O Dementia	1461.	1461.
Dementia Monitoring	66h..	XaMJC
Dementia Annual Review	6AB..	XaMGF
Cognitive Decline	28E..	*No equivalent*
Impaired Cognition	28E3.	Ua189
Severe Cognitive Impairment	28E2.	Xaagk
Moderate Cognitive Impairment	28E1.	Xaagj
Confusion	R009.	R009.
Confused	2841.	2841.
Intermittent confusion	-	Xa1sZ
Poor short term memory	-	X75xH
Poor long term memory	-	X75xC
Memory Impairment	-	X75xU
Short term memory problems	1B1A1	*No equivalent*
Forgetful	28G..	X75xV
Memory lapses	-	Ua197
Age-associated memory impairment	-	X00RT
Onset of confusion	-	Ua1W9
Referral to Memory Clinic	8HTY.	XaJua
Referral to psychiatrist for elderly mentally ill	8H4D.	8H4D.
Mild Cognitive Impairment (not in last 12 months)	28E0.	Xaagi
Mild Cognitive Disorder (not in last 12 months)	Eu057	X00RS
Memory Disturbance (mild)		XE1bq

Additional EMIS Local codes

EMIS dementia codes	EMISNQDD2, EMISNQDV1, EMISNQDD1, EMISNQDD3
Dementia Review	EMISNQDE1
Other	EMISNQIM12

Drugs included

Donezepil (Aricept® , Aricept Evess®)
Galantamine (Reminyl®, Reminyl® XL)
Rivastigmine (Exelon®)
Memantine hydrochloride (Ebixa®)

Appendix 2 – Dementia Prevalence and Implications for QOF Payments 2016/17

Download from:
http://www.yhscn.nhs.uk/media/PDFs/mhdn/Dementia/Quality%20Improvement%20Awards/Dementia%20prevalence%20and%20QOF%20payments.pdf

Dementia Prevalence and Implications for QOF Payments 2016/17	
An important feature of QOF is the establishment and maintenance of disease registers. There are 5 QOF points available for establishing and maintaining a dementia register. It is the responsibility of the practice to demonstrate the systems that are in place to maintain a high quality register. Running the dementia quality toolkit every 6 months will give demonstrable help. The worked example below also demonstrates the financial benefit of ensuring that anyone with a dementia diagnosis is added to the register and that patients who present with symptoms are investigated and referred on as appropriate.	
PRACTICE 1 – 10,000 PATIENTS Low dementia prevalence, high point achievement	**PRACTICE 2 – 10,000 PATIENTS High dementia prevalence, less point achievement**
Average £ per QOF point = £165.18*	Average £ per QOF point = £165.18*
Dementia National Prevalence = 0.74%**	Dementia National Prevalence = 0.74%**
Practice prevalence = 0.4%	**Practice prevalence = 1.0%**
Dementia point value drops to £89.29	**Dementia point value increases to £223.22**
Dementia points achieved for ongoing management = 45 (maximum)	Dementia points achieved for ongoing management = 35
TOTAL INCOME FOR DEMENTIA = £4017.89	TOTAL INCOME FOR DEMENTIA = £7812.57

Income increase by adding 10 patients to the register	**£1004.47**
Income increase by adding 20 patients to the register	**£2008.95**
Income increase by adding 30 patients to the register	**£3013.42**

This example is to be used for illustration purposes only. It is not based on real GP practice data and uses the source data shown below for calculation.

* Source: http://www.pulsetoday.co.uk/your-practice/qof/value-of-qof-point-increases-to-165/20031606.fullarticle

** Source: https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data#page/0/gid/1938132811/pat/6/par/E12000004/ati/102/are/E06000015 (2014/15 data)