UNIVERSITY OF BIRMINGHAM AND UNIVERSITY OF YORK HEALTH ECONOMICS CONSORTIUM

(NICE EXTERNAL CONTRACTOR)

Development feedback report on piloted indicators

QOF indicator area: Dementia

Pilot period: 1st April 2012 - 30th September 2012

Potential Output: Recommendations for NICE menu

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Background

As part of the NICE-managed Quality and Outcomes Framework (QOF) process, all clinical and health improvement indicators are piloted, using agreed methodology, in a representative sample of GP practices across England, Scotland, Wales and Northern Ireland.

The aim of piloting is to test whether indicators work in practice, have any unintended consequences and are fit for purpose.

Piloted indicators

The percentage of patients with dementia with the contact details of a named carer on their record.

The practice has a register of patients who are carers of a person with dementia.

The percentage of carers (of a person with dementia) who have had an assessment of their health and support needs in the preceding 12 months.

Number of practices participating in the pilot:	39
Number of practices withdrawing from the pilot:	3
Number of practices where staff were interviewed:	36

(33 GPs, 7 Practice Nurses, 16 Practice Managers, 1 Health Care Assistant, 2 Administrative Managers = 59 primary care staff most involved in the QOF pilot)

Assessment of clarity, reliability, feasibility, acceptability and implementation

Clarity

- Indicator wordings as stated were rated as clear and unambiguous by the experts and frontline GPs.
- The HSCIC has confirmed that they have been able to write Business Rules (and/or an Extraction Specifications).

Reliability[1] and Feasibility

Indicator	Feasibility	Reliability	Implementation
1	**2**	**2***	**2**
2	**2**	**2***	**2**
3	**2**	**2***	**2**
GPES conversion			**3**

**** General comment***

The reliability of this indicator isn't necessarily down to the technical details of the extractions, but more about how the codes are to be used and the required guidance products to ensure people are coding properly.

Acceptability

Please also see Appendix A.

General comments

These three indicators raised general issues over the definition of a carer. Many practices felt that people did not see themselves as carers and therefore did not respond to invitations to become part of a register/add contact details/have a health check. Self identification as a carer varied between individuals and cultures (with some people seeing a carer role as part of normal family life).

The percentage of patients with dementia with the contact details of a named carer on their record:

29/36 would include this in QOF

3/36 would not include this in QOF

4/36 were ambivalent about inclusion.

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[1] HSCIC provide guidance on whether the piloted indicators are, from a business rule perspective, suitable to become 'live' indicators. A notional 'scoring' system is used:

1. No problems to implement in live with other indicators
2. Minor re-work before it can go live with other indicators
3. Major re-work but do-able without recourse to anyone outside of the process
4. Major considerations to be made before the indicator can go live - possibly need to speak to CFH / suppliers
5. Not feasible

The practice has a register of patients who are carers of a person with dementia:

22/36 would include this in QOF

7/36 would not include this in QOF

7/36 were ambivalent about inclusion.

The percentage of carers (of a person with dementia) who have had an assessment of their health and support needs in the preceding 12 months: See Appendix B.

15/36 would include this in QOF

14/36 would not include this in QOF

7/36 were ambivalent about inclusion.

Acceptability indicator 1 (carer's contact details)

On the whole, this indicator was seen as *"straight forward" "in the patient's best interest"* and *"a must".* GPs would want to share the information with local out of hours services. They also liked the fact that this indicator was focused on vulnerable groups.

'Well we always wanted to put their carer's details, even without this [yeah] before this came and we have subsection in system 1 that family, medical so anything we can put in the family that again they give us a lot of, um, dividing things like son, daughter, daughter-in-law, friends, neighbour so, so this was already in, in there but it is nice to know who is the main carer [yeah] and what is their contact number in case of any problem we can talk to them because dementia itself, person he will not be able to remember or he may not be able to contact us directly and it is good to have and we pass this information to out of hours as well because these are the doctors who are dealing with mostly happens over the weekend [yeah] and nights and after hours so if they have some details about the patient information on their records which we share between System 1 and I think all the doctors are using all sort of information that they pass it on if patient is allergic to something or patient is patient has got any particular needs then we make sure that it is passed along to out of hours doctors [lovely] for the organisation we work for.' (ID32)

With regards to consent, a small number of practices noted the difficulty in gaining this from patients with dementia. Though gaining consent from carers was much less problematic, many practices noted that this had generally been implicit.

Two challenging, though rare, situations were raised: situations where a number of people (e.g. neighbours) shared the care of a dementia patient and situations where care may come from *"squabbling siblings"* (ID27).

'We, we managed to get all of the contact details and again, the carers are, you know, they're perfectly happy to give them and - we did have some erm people err who were formally diagnosed who didn't have formal or informal carer, but they were okay because they were just generally looked after in the neighbourhood. The neighbours looking on them and, you know, that sort of thing. 'Oh yeah, they're all right,' whoever looks in, you know, because they want to be independent.

So we didn't have any carers who didn't want to be on the register. We just had a couple of patients who didn't have a formal or informal carer.' (ID38)

Acceptability indicator 2 (dementia carers' register)

This register was met with a luke warm response from most practices, who saw it as a largely administrative task, better carried out by social services. Almost all questioned whether it had any value at all in terms of improving health outcomes but in view of current attention on carers more generally, could see why it had been included in the QOF pilot. Seven practices were ambivalent – they could see its relevance but felt that is was not a high enough priority in primary care to be included in QOF.

'What value will it be really? I mean what is the value to the carer or value to the mental patients, I don't know what it is that we are looking for there really. I couldn't get the…it is not…I try to clear what is the value, you know, the evidence.' (ID30)

'I think if it's being covered by the care, the medical or primary care services for the patient they should pick that up so I don't see that as being…I can see the relevance of it but I don't think it has as high a priority as knowing that the patient has a carer.' (ID20)

Significant concerns even from practices who said they would include the indicators in live QOF included worries about the accuracy of the register, related to the subjectivity of being a carer. As carers self identified, there were limited ways of validating the register which left it potentially open to inflation in order to boost prevalence and therefore payment. The register also required constant updating which had ongoing workload implications.

Hard-to-reach group of carers (those that did not regularly attend surgery and/or were caring for patients registered elsewhere and younger carers who worked and those who did not self identify as carers) remained difficult to include in the register.

Acceptability indicator 3 (carers' assessment)

Only 3 practices of the 36 actively engaged with this indicator throughout the entire pilot. A small number of practices did try to perform the assessment opportunistically and most discussed the practicalities of offering the assessment with the wider practice team. The poor level of engagement however suggests this indicator was not generally acceptable to practices. The response rate of 15/36 for acceptability was based largely on theoretical discussions with the wider practice team.

'Mainly a question of workloads and the chances are in the vast majority of patient because they come to this practice anyway and the age range you're talking about they probably have medical problems where they will be seen routinely anyway so it just put another sort of workload burden on top of that where it wasn't really necessary…yeah, someone with high blood pressure would be seen every six months anyway.' (ID14)

There were four main reasons why this indicator was only seen as acceptable by 15/36 practices- the minority of practices:

1. Practices found the indicator unacceptable because they felt it was making carers' health into *'an industry'*. They worried it would become a robotic process that missed the point.

'Guidance could be less specific – just x, y, z should be covered – rather than having to tick individual parts of it (so, bundle), otherwise feels robotic & misses point.' (ID18)

2. They also felt that being called in for a face to face review might add an extra burden onto carers' already busy lives.

3. They also felt that since the check was predicated on being included on a register that was itself open to inflation and inaccuracies, this also affected the reliability of the indicator.

4. Most practices were concerned that the assessment would be *"one size fits all"* whereas carers were a heterogeneous group in terms of age and in their caring role e.g. some might be involved in heavy lifting. An inflexible template was therefore not an ideal vehicle to assess needs.

Practices who had fully engaged with this indicator asked patients about their views of the assessment and none reported anything other than positive comments from carers themselves.

'We, we didn't find it too difficult at all. Obviously we'd be very diplomatic with the patient if the patient is the person with the dementia, because, obviously, we need to be cautious what we're doing there. So how we worded that was - had to be careful. We did most of it by telephone, and the doctors did some face to face while the people were in the surgery. Erm and we found that all of the carers were cooperative. We didn't have any that refused erm to give their contact details. So we found in - I, I think, you know, the patients in general, I think that's one of the questions further down, I think the patients in general found it nice that somebody was interested in the fact that they were a carer of a person with dementia and recognised perhaps the problems that they might have, with that particular type of caring'. (ID38)

Acceptability recommendation indicator 1 (carer's contact details)

- There is a high degree of confidence that there are no major barriers/ risks/ issues/ uncertainties identified from the pilot *in terms of acceptability* that would preclude this indicator from being implemented.

Acceptability recommendation indicator 2 (dementia carers' register)

- There are barriers/ risks/ issues/ uncertainties identified from the pilot *in terms of acceptability* that in themselves may not be sufficient to prevent an indicator being recommended by the AC, but require the particular attention of the AC.

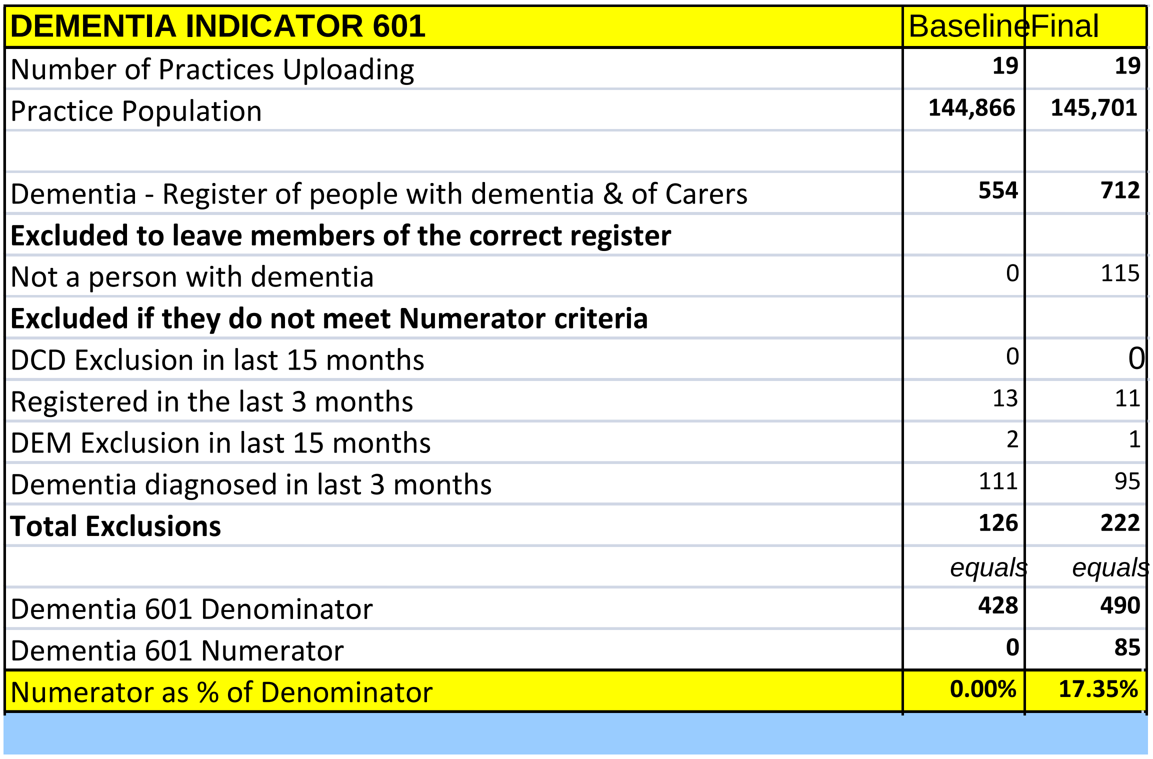
Acceptability recommendation indicator 3 (carers’ assessment)

- There are barriers/ risks/ issues/ uncertainties identified from the pilot *in terms of acceptability* that in themselves may not be sufficient to prevent an indicator being recommended by the AC, but require the particular attention of the AC.

IMPLEMENTATION

1. Assessment of piloting achievement

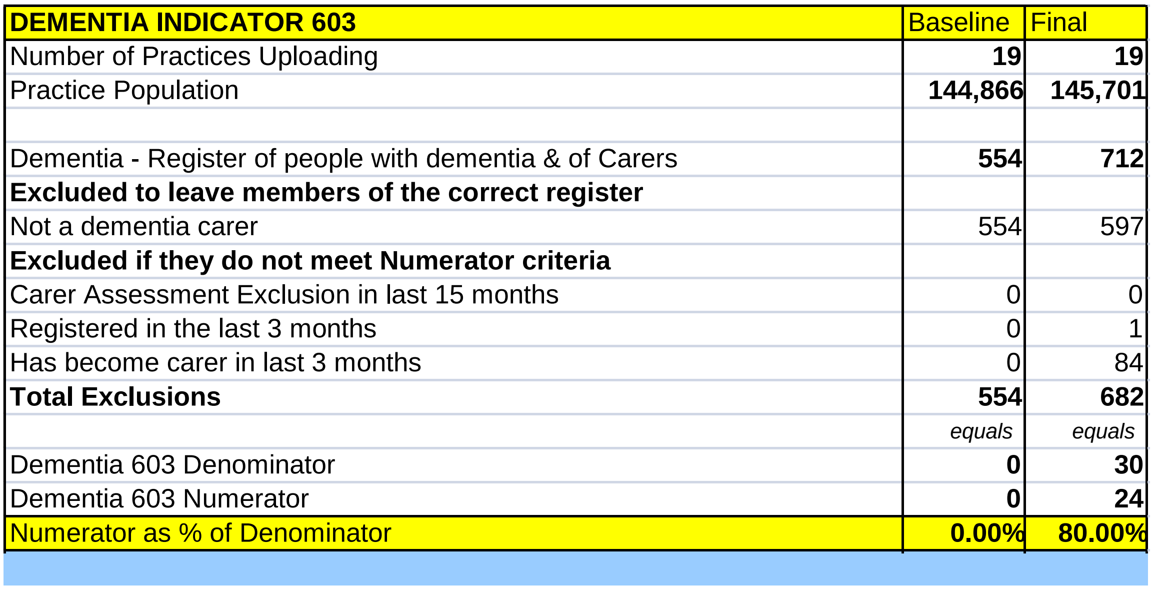
Data are available for indicator 1 (carer’s contact) and 3 (health check) but not 2 (carers’ register).



DEMENTIA INDICATOR 601	Baseline	Final
Number of Practices Uploading	**19**	**19**
Practice Population	**144,866**	**145,701**
Dementia - Register of people with dementia & of Carers	**554**	**712**
Excluded to leave members of the correct register		
Not a person with dementia	0	115
Excluded if they do not meet Numerator criteria		
DCD Exclusion in last 15 months	0	0
Registered in the last 3 months	13	11
DEM Exclusion in last 15 months	2	1
Dementia diagnosed in last 3 months	111	95
Total Exclusions	**126**	**222**
	equals	*equals*
Dementia 601 Denominator	**428**	**490**
Dementia 601 Numerator	**0**	**85**
Numerator as % of Denominator	**0.00%**	**17.35%**

In the baseline upload, 0% of patients achieved indicator because there was no read code available.

In the final upload, 17% of patients achieved the indicator.



DEMENTIA INDICATOR 603	Baseline	Final
Number of Practices Uploading	**19**	**19**
Practice Population	**144,866**	**145,701**
Dementia - Register of people with dementia & of Carers	**554**	**712**
Excluded to leave members of the correct register		
Not a dementia carer	554	597
Excluded if they do not meet Numerator criteria		
Carer Assessment Exclusion in last 15 months	0	0
Registered in the last 3 months	0	1
Has become carer in last 3 months	0	84
Total Exclusions	**554**	**682**
	equals	*equals*
Dementia 603 Denominator	**0**	**30**
Dementia 603 Numerator	**0**	**24**
Numerator as % of Denominator	**0.00%**	**80.00%**

In the baseline upload, no patients made it through to the denominator because although read codes were available, they were not in general usage. In the final upload, 80% of patients achieved this indicator. Although this represents a significant increase these reviews were only undertaken in three practices. This reflects the general feeling from the qualitative interviews of a lack of engagement with this indicator.

2. Changes in practice organisation

Specific comments indicator 1 (carer's contact details)

The key issue for recording carer's contact details was that most practices said they had the information somewhere in the patient's notes but that it was not read coded. Three practices made a point of specifically checking this issue and reported information in 50%, 70% and 86% of notes (though not necessarily coded in a way that would be easily extracted).

In cases where the contact details of a named carer could not already be found in the patient records, many practices telephoned the patient to find the carer's details or asked opportunistically in a consultation.

Specific comments indicator 2 (dementia carers' register)

Practices reported populating this register using a number of approaches including:

- new patient checks (most frequently mentioned)
- the dementia register
- information in the practice (notice board/website/electronic message board) encouraging self identification

- flu jab information encouraging self identification
- practice tacit knowledge through a brainstorming session

Specific comments indicator 3 (carers' assessment)

Almost all practices felt the assessment should be face to face rather than on the phone and probably with the practice nurse first of all with referral onto the GP if the nurse felt this was necessary. Two practices described the process they took in great detail. One identified 12 people who were eligible and called 11 of the 12 in for an assessment. However they did not find any new conditions or problems because they already knew these patients well. Another practice identified 27 people and found that they'd recently reviewed 24 anyway. These two worked examples however are at odds with the fears of many practices about the workload associated with discovering new unmet needs.

'I would see them being done face to face, yeah.' (ID21)

3. Resource utilisation and costs

Specific comments indicator 1 (carer's contact details)

Perceptions of the resource utilisation of this indicator varied. It was described as *"just an admin task"* that took *"an hour at most"* to an *"onerous"* one that required *"trawling"* through records. However, this was recognised as a 'set-up' workload that would require administrative time to complete retrospectively. Prospectively, the resource utilisation for this indicator would not present a significant burden.

Specific comments indicator 2 (dementia carers' register)

Canvassing whole practice populations would have implications for resources, as would continually checking with carers to keep lists up to date. Most practices would rather employ strategies to encourage carers to self-identify but the impact of these against return was questioned. During the pilot, 3 practices used specific strategies to encourage self-identification but no patient responded in any of the three practices. One practice used a community newsletter to advertise the existence of the new register and assessment and yet had no one come forward to use the service.

'Yeah we've changed our patient registration questionnaire to include whether they are a patient here, obviously signing up here, whether they are a carer of someone else, whether if they are a carer of someone else of what they have, what's wrong with them, whether they have dementia or whether it's just age or whatever so that then helps us to code and then also helps us to highlight those that are going to require…but as of yet we've not had anybody.' (ID36)

‘We tried to identify these people, posters in the waiting room, I think we even put it in the local community newsletter didn't we? And people just didn't come forward.’ (ID33)

Specific comments indicator 3 (carers’ assessment)

Although many practices felt that the main outcome of a check would be to signpost to other support mechanisms, many GPs were worried that the check would *“open Pandora’s box”* (ID28) and that significant resources would be needed both within the practice and in the community to deal with issues raised.

4. Barriers to implementation

Specific comments indicator 1 (carer’s contact details)

The term carer will need to be clearly and unambiguously defined.

Specific comments indicator 2 (dementia carers’ register)

The need to make the register as accurate and up to date as possible needs to be highlighted. Practices experienced practical difficulties with creating this register, especially when trying to identify people who cared for a person with dementia who was registered elsewhere. Practices relied upon patients identifying themselves as carers meaning that registers are likely to be systematically incomplete and impossible to verify thus making the indicator unreliable.

Specific comments indicator 3 (carers’ assessment)

The success of the assessment depends on the accuracy of the register. There were particular concerns about the content of the assessment that have implications for the putative cost effectiveness of the indicators. The focus of the economic assessment considered psychological intervention for carers with depression. YHEC concluded that the indicator for assessment is highly cost effective and there is a strong rationale for awarding at least 10 points for 90% achievement. However piloting found that engagement with this indicator was very limited which suggests that the 90% achievement is a considerable over estimate. More importantly (given that practices may well engage more if it is introduced into live QOF), there were indications from the pilot practices that the depression screening questions that were included in the assessment template were not used. It’s important to remember that this pilot was also running at a time when the generic QOF depression indicators had been subject to considerable debate, discussion and revision.

‘Well we tend not to code, well you see now…we have very few patients now coded as depression because the QOF points for depression actually made us stop coding people as depressed.’ (ID4)

One practice felt that they would only be picking up *'natural reactive depression'* related to the act of being a carer, and that there was therefore little they could do to improve or ameliorate the circumstances. Another practice suggested that rather than actively screening every carer of a person with dementia for depression, they would only screen those whose answers about other issues raised cause for concern. This would keep the assessment less 'box like' and more reflexive and responsive to the needs of the individual.

' It, it…well obviously by talking to them if you think that they are clinically showing signs of depression…we don't ask direct question unless they seemed well into themselves. Or, or in way in a way we think we need to prod or, you know, open up little bit more then we can ask appropriate questions.' (ID32)

5. Assessment of exception reporting

Specific comments indicator 1 (carer's contact details)

None.

Specific comments indicator 2 (dementia carers' register)

None.

Specific comments indicator 3 (carers' assessment)

None.

6. Assessment of potential unintended consequences

Specific comments indicator 1 (carer's contact details)

Three patients expressed a concern about being identified as a carer since this was not a role they perceived as relevant to themselves.

Specific comments indicator 2 (dementia carers' register)

There were also very occasional concerns that people may be suspicious of self identifying if they were claiming e.g. for Disability Living Allowance or other allowances.

'Well…the thing is certain things are very, you know, people who claim carer's allowance and attendance allowance and housing benefit and things like that, generally they are a bit reluctant to talk about their benefits. They're getting it, [yeah] therefore they don't divulge...Yeah, because

they're getting money. [right] And you know people who may get attendance allowance and carer's allowance for the mother who may be living in Timbuktu with somebody. [right] You know what I mean?' (ID37)

The register is also open to potential inflation by practices as its accuracy is extremely difficult to verify.

Specific comments indicator 3 (carers' assessment)

A minority of practices worried about patient choice in the context of a health check. One practice worried that carers would be worried about attending in case they were found to be too unwell to be a carer.

Implementation recommendations

Implementation recommendation indicator 1 (carer's contact details)

- There is a high degree of confidence that there are no major barriers/risks/issues/ uncertainties identified from the pilot *in terms of implementation* that would preclude the indicator from being implemented.

Implementation recommendation indicator 2 (dementia carers' register)

- There are barriers/risks/issues/uncertainties identified from the pilot that would preclude the indicator being implemented. (based on concerns over register accuracy and indicator reliability)

Implementation recommendation indicator 3 (carers' assessment)

- There are barriers/risks/issues/uncertainties identified from the pilot that would preclude the indicator implemented.

Assessment of overlap with existing QOF indicators and potential changes to existing QOF indicators

Many practices noted the overlap of these indicators with DEM 1 (The practice can produce a register of patients diagnosed with dementia), DEM 2 (The percentage of patients diagnosed with dementia whose care has been reviewed in the preceding 15 months), the recent CQC registration process for primary care in England (see Appendix C and http://www.cqc.org.uk/organisations-we-regulate/gps-and-primary-medical-services/registering-cqc-information-gps-and-oth-4) and also with elements of the NHS Health Check in England (see http://www.healthcheck.nhs.uk/) . DEM2 includes the support needs and impact of caring on the carer. CQC outcomes 1, 4 and 17 include a focus on carers e.g. respecting and involving people who use services. The NHS Health Check is for people aged 40-74 in England. The programme aims to help prevent heart disease, stroke, diabetes and kidney disease. Everyone between the ages of 40 and 74, who has not already been diagnosed with one of these conditions, will be invited (once every five years) to have a check to assess their risk of heart disease, stroke, kidney disease and diabetes and will be given support and advice to help them reduce or manage that risk. Theoretically therefore elements indicator 3 might have been recently offered to a carer. The overlap with DEM2 is also something highlighted by the focus group with frontline GPs during the indicator development process.

Many practices wondered why the indicators were restricted to dementia and not focused on all carers.

Overall recommendation indicator 1 (carer's contact details)

There is a high degree of confidence that there are no major barriers/risks/issues/ uncertainties identified from the pilot that would preclude the indicator from being recommended for publication on the NICE menu of indicators

Overall recommendation indicator 2 (dementia carers' register)

There are barriers/risks/issues/uncertainties identified from the pilot that would preclude the indicator being published on the NICE menu of indicators.

Overall recommendation indicator 3 (carers' assessment)

There are barriers/risks/issues/uncertainties identified from the pilot that would preclude the indicator being published on the NICE menu of indicators.

Suggested amendments to indicator 1 (carer's contact details)

None.

Suggested amendments to indicator 2 (dementia carers' register)

None.

Suggested amendments to indicator 3 (carers' assessment)

One practice felt that the check should be *offered* rather than performed.

Appendix A: Indicator details

NICE Quality Standard

Quality statement 3: People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and support options in their local area.
Quality statement 4: People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care that identifies a named care coordinator and addresses their individual needs.
Quality statement 6: Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.

These quality statements and potential indicators were discussed with four topic experts (Professor Steve Iliffe, Professor Louise Robinson, Professor Jill Manthorpe and Professor Tim Kendall) on 30th November 2011. The issues discussed in relation to these indicators and outcomes of these discussions are detailed in Table 1.

Table 1: Dementia care indicators

NICE recommendation/ quality statement	**Potential indicator**	**Questions/ issues for expert group discussion**	**Outcome of expert discussion**
Quality statement 3: People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and support options in their local area.	The percentage of people diagnosed with dementia in the preceding 1 April to 31 March who have been given written and verbal information about: Their condition Treatment options and Local support within 6 months of the diagnosis.	Would need to code each element separately. Would practices be able to exception report against discrete elements? What sort of information should be covered by each of these elements and how detailed should it be? Only focuses upon new diagnoses and expects information to be given within 6 months – are there any unintended consequences to this	It was agreed that this was intended to be a secondary care responsibility.
Quality statement 4: People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care that identifies a named care coordinator and	The percentage of people with dementia with a named individual with responsibility to coordinate care across health and social services.	Would this be applicable to all patients or only those under the care of social services? How often should this be reviewed/ updated? Once ever, annually? Who are appropriate individuals to act as care coordinators?	Again this was felt to be a secondary care responsibility. The experts felt strongly that we should try to develop an indicator which would address care planning including longer term care needs such as Lasting Power of Attorney and end of life

addresses their individual needs.			care. It was agreed to take the following indicator to the GP focus group: 'The percentage of patients with dementia with a written care plan, reviewed in the preceding 6 months'. The expert group highlighted the importance of this applying equally to patients living in care homes.
Quality statement 6: Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.	The practice has a register of patients who are carers of a person with dementia. The percentage of carers (of a person with dementia) who	This has always been dismissed in negotiations as too difficult. The key here is that it is the carer who is registered with the practice. Will need to explore in pilot the numbers of carer/patient dyads registered with the practice and the numbers who are carers of patients registered elsewhere. NB: practices are already rewarded under Management 9 for the identification of carers	The experts felt that there were two key issues here: Identifying if the person with dementia has a carer and how to contact them as this information can be scattered across medical records in free text and Supporting carers themselves. Given this, it was agreed to take the following indicator to the GP focus group: 'The percentage of patient with dementia

	have had an assessment of their health needs in the preceding 12 months. The percentage of carers (of a person with dementia) who have had a review of their support needs in the preceding 12 months.	and for advising them on how to get further support. Will need to define what this assessment should cover. Dependent upon practices being able to create a register of patients who are carers of a person with dementia. Requires the practice to record carers support needs – how feasible is this? Will need to define ‘support needs’.	with a named carer’. The key health needs identified were those relating to mental health and depression and anxiety in particular. Support needs included access to respite as well as information about voluntary sector support groups. It was suggested that these indicators could be combined and so the following indicator was taken to the GP focus group: ‘The percentage of carers (of a person with dementia) who have had an assessment of their health and support needs in the preceding 12 months’.

The final set of indicators then taken forward for discussion with frontline GPs was:

1. The percentage of people with dementia with a written care plan reviewed in the previous 6 months.
2. The percentage of people with dementia with a named carer.
3. The practice has a register of patients who are carers of a person with dementia.
4. The percentage of carers (of a person with dementia) who have had an assessment of their health and social needs in the preceding 12 months.

Focus group discussion with frontline GPs

A focus group was held on 8th December 2011 with 12 front line GPs recruited via the West Midlands Faculty of the Royal College of General Practitioners. They participated on a voluntary basis. The majority were male (female = 3), aged between 30-55 years and included three QOF Assessors. There were also two representatives from PRIMIS+ at the meeting and a representative from NICE. Prior to the meeting the GPs were provided with written detail of the proposed indicators and the underpinning NICE recommendation/ quality standard. This included details of specific issues which we wanted them to discuss in relation to each indicator. The purpose of this meeting was to consider the clarity, feasibility and validity of the indicators, to suggest improvements where possible and to highlight specific issues that would need to be explored during piloting. Each indicator was discussed in turn.

Dementia care

1. The percentage of people with dementia with a written care plan reviewed in the previous 6 months.

There was a general consensus across the focus group that this was not a core part of primary care business, especially when the content of a care plan was poorly defined at a national level. However, the QOF assessors present commented that the existing DEM2 appears to be addressed in a variable manner by practices and that there is some scope for improvement. The consensus was that we need to better stipulate the essential aspects of care which should be delivered as part of DEM2 rather than develop new indicators which would be as difficult to monitor.

This indicator is not to be progressed to piloting.

2. The percentage of people with dementia with a named carer.

Most of the discussion focused on the purpose of this indicator. It was agreed that it should focus on improving the documentation of named carers in the medical record of the person with dementia. It was suggested that the indicator should be reworded to make this more explicit. Concerns were also raised about confidentiality which will need to be explored further with the MPS/MDU and possibly the BMA.

2. The practice has a register of patients who are carers of a person with dementia.

   The main focus of the discussion was around defining what was meant by a carer. It was noted that the definition of a carer given for Management 9 focuses on keeping the cared for person at home in the community whereas the discussion with topic experts had highlighted that a person continued to be a carer even if the person being cared for went into residential care. It was agreed that any definition would need to exclude occupational carers unless they were also lay carers.

Final piloted indicators

The percentage of patients with dementia with the contact details of a named carer on their record.
The practice has a register of patients who are carers of a person with dementia.
The percentage of carers (of a person with dementia) who have had an assessment of their health and support needs in the preceding 12 months.

Appendix B

Clinical template for practices for indicator 3: ***The percentage of carers (of a person with dementia) who have had an assessment of their health and support needs in the preceding 12 months.***

Purpose of this indicator

- To encourage practices to participate in the ongoing support of patients who are carers.
- To enable early identification of health and social problems arising from a person's caring role.

Implementation details

This assessment should be offered to all patients identified as being carers of a person with dementia.

Content of the indicator

In 'Recognised, Valued and Supported: Next Steps for the Carers Strategy'[2] carers identified five outcomes as key to their wellbeing: emotional support, monitoring their own health, being informed (about the condition of the person they care for as well as services available for themselves as carers), having a voice (being recognised as an expert in the care of the person they care for) and having a break.

Emotional support

The evidence base is strongest in relation to the emotional impact of caring, specifically the risk of depression[3,4]. Therefore we would like you to complete the two Whooley depression screening questions:

1. *During the last month, have you often been bothered by feeling down, depressed or hopeless?*
2. *During the last month, have you often been bothered by having little interest or pleasure in doing things?*

If the response to either of these questions is 'yes', further evaluation is warranted using a tool such as the Patient Health Questionnaire (PHQ9).

Monitoring own health

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[2] http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_122393.pdf

[3] Pinquart and Sorensen (2003) *Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis*, Journal of Gerontology: Psychological Sciences, 58B (2): P112-128.

[4] Pinquart and Sorenson (2003) *Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis,* Psychology and aging, 18(2): 250-267.

There is some evidence to suggest that carers are inclined to neglect their own health. They are also potentially older with their own chronic health conditions which require monitoring [5,6]. As well as monitoring any long-term condition the carer may have the RCGP suggests that you should consider undertaking a general health review, to include:

- Recording of blood pressure and pulse
- Body mass index
- Smoking status
- Alcohol consumption and illicit drug use
- Diet and levels of physical activity
- Urine dipstick for glucose
- Review of any ongoing medical problems including physical problems as a result of lifting and handling
- Reinforcement of the benefits of routine screening programmes e.g. breast, cervical and bowel cancer screening
- Advice re: flu vaccination

Being informed, having a voice and having a break
Please consider informing carers of their rights to a social services assessment, local support services including respite care and the availability of carer's allowance.

Carers should also be provided with condition specific information.

The specific detail of what should be included in a carer's assessment in primary care is undecided. With the exception of the Whooley depression assessment questions, the aspects of care detailed above are suggestions only. In piloting this indicator we are looking for your help in determining what the minimum criteria should be should this indicator progress to live QOF. We appreciate that this will have to be freetext which can be cumbersome and time consuming, but will really help us work out the content of the check up for live QOF.

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[5] Schultz, O'Brien, Bookwala and Fleissner (1995) *Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates and causes,* The Gerontologist 35(6): 771-791.

[6] Vitaliano and Zhang (2003) *Is caregiving hazardous to one's physical health? A meta-analysis,* Psychological Bulletin, 129(6): 946-972.

Appendix C: 16 CQC standards that most directly relate to the quality and safety of care

Outcome 1: Respecting and involving people who use services

People should be treated with respect, involved in discussions about their care and treatment and able to influence how the service is run.

Outcome 2: Consent to care and treatment

Before people are given any examination, care, treatment or support, they should be asked if they agree to it.

Outcome 4: Care and welfare of people who use services

People should get safe and appropriate care that meets their needs and supports their rights.

Outcome 5: Meeting nutritional needs

Food and drink should meet people's individual dietary needs.

Outcome 6: Cooperating with other providers

People should get safe and coordinated care when they move between different services.

Outcome 7: Safeguarding people who use services from abuse

People should be protected from abuse and staff should respect their human rights.

Outcome 8: Cleanliness and infection control

People should be cared for in a clean environment and protected from the risk of infection.

Outcome 9: Management of medicines

People should be given the medicines they need when they need them, and in a safe way.

Outcome 10: Safety and suitability of premises

People should be cared for in safe and accessible surroundings that support their health and welfare.

Outcome 11: Safety, availability and suitability of equipment

People should be safe from harm from unsafe or unsuitable equipment.

Outcome 12: Requirements relating to workers

People should be cared for by staff who are properly qualified and able to do their job.

Outcome 13: Staffing

There should be enough members of staff to keep people safe and meet their health and welfare needs.

Outcome 14: Supporting workers

Staff should be properly trained and supervised, and have the chance to develop and improve their skills.

Outcome 16: Assessing and monitoring the quality of service provision

The service should have quality checking systems to manage risks and assure the health, welfare and safety of people who receive care.

Outcome 17: Complaints

People should have their complaints listened to and acted on properly.