

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

QUALITY AND OUTCOMES FRAMEWORK (QOF) INDICATOR DEVELOPMENT PROGRAMME

Consultation report on piloted indicator(s)

QOF indicator area: Dementia – Support for carers

Consultation period: 07/01/2013 – 04/02/2013

Potential output: Recommendations for NICE Menu

Indicator(s) included in the consultation

1. The percentage of patients with dementia with the contact details of a named carer on their record.
2. The practice has a register of patients who are carers of a person with dementia.
3. The percentage of carers (of a person with dementia) who have had an assessment of their health and support needs in the preceding 15 months.

Summary of responses: general comments on indicator(s)

Overall the proposed dementia carer indicators were supported by stakeholders as useful additions to the QOF and representative of good practice.

A number of stakeholders including the Alzheimer's Society and the British Psychological Society commented that some people with dementia do not have a carer. Stakeholders also commented that people in the early stages of dementia usually do not require a carer and can lead active and independent lives, possibly for several years, without a carer. If measures are implemented with the intent that a carer is nominated once a diagnosis is made, this may be interpreted negatively in terms of a person's independence and expectation of disease progression.

A number of stakeholders commented that the indicators should apply to all carers and should not be restricted to just carers of people with dementia.

Stakeholders highlighted that currently there is only a single generic code for “carer” in GP clinical information systems that can be used, and that specific codes for caring for dementia do not exist.

Stakeholders also highlighted a lack of clarity in the definition of a carer and potential issues if the named carer is registered at a different general practice to the person with dementia.

Considerations for Advisory Committee

The specific issues that the Advisory Committee is asked to consider when making recommendations on which indicators should be published on the NICE menu for the QOF are stated below.

These issues are also addressed in the indicator development reports which will include suggestions for possible amendments to how the indicators should be specified following piloting and public consultation.

The Advisory Committee is asked to consider:

- The point at which someone newly diagnosed with dementia should be asked about their carer.
- The implications for practice when the person with dementia is resident in a nursing home.

Summary of responses: comments by indicator

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

Overall, the inclusion of the record of contact details of a carer for a person with dementia was well received by stakeholders. Stakeholders commented that it would be beneficial to have the contact details of carers on record and that this represents good practice.

Some stakeholders commented that this should not be restricted to carers of people with dementia, as this would be beneficial to a range of conditions. For example one stakeholder commented that a potential unintended consequence was that GP surgeries have recently been encouraged to identify young carers when dealing with parents with chronic ill health, disability, mental ill health or affected by substance misuse. It was thought that only targeting carers of people with dementia will mean there will be no incentive for GPs to identify and support these young carers.

Stakeholders noted that people with dementia may not have a carer for many reasons. For example, they may be out of touch with family members. Stakeholders also commented that people in the early stages of dementia usually do not require a carer and can lead active and independent lives, possibly for several years, without a carer. If an indicator was implemented with the intent that a carer is nominated when a diagnosis is made, this may be interpreted negatively in terms a person's independence and expectation of disease progression. Stakeholders stated that sensitivity and clinical judgement was important for this indicator in deciding at which point the person with dementia should be approached for details of a carer to put on the register.

One stakeholder commented that the indicator required a clear definition of who would be included as a carer. They also raised the question of whether people under the care of social services would be exception reported if they did not have a carer.

It was also argued that it may be difficult to capture the details of carers with the current GP clinical information systems.

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

A number of stakeholders including the Royal College of General Practitioners (RCGP) supported this proposed indicator. Stakeholders pointed to evidence that carers of people with dementia have worse physical and mental health

than other carers. Therefore GPs should be able to identify these carers and undertake regular assessment of their health and needs.

Some stakeholders commented that this indicator represented good practice, but felt that all carers, and not just those caring for people with dementia, should be covered. It was argued that a large number of people caring for people with other conditions have their health and wellbeing adversely affected by their caring role. These carers may be unaware of the support from social services and the voluntary sector that is available.

Some stakeholders who supported the indicator felt that the indicator would only be feasible if the main carer is registered with the same GP practice as the person with dementia.

One stakeholder also felt that guidance would need to be clear that this indicator may require people to self-declare their carer status in some circumstances. The stakeholder commented that failure to do this would result in this indicator becoming a screening indicator.

One stakeholder suggested that a register of carers, on its own, would not improve quality of care. They suggested that the size of the register should be considered in terms of the practice list size for it to be an accurate reflection in terms of numbers. The importance of keeping the register updated was also highlighted.

Stakeholders highlighted that currently there is only a single generic code for “carer” in GP clinical information systems that can be used, and that specific codes for caring for dementia do not exist.

NHS Employers queried whether people would be exception reported if they lived in a nursing home and if practices that serve nursing homes could be unfairly disadvantaged if they are required to exception report large numbers of their registered patients.

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.

Stakeholders in general were positive about the inclusion of this potential new indicator. One stakeholder commented that the link between caring and ill health is well demonstrated and health assessments of carers would enable health issues be identified.

The RCGP supported the intent of this indicator but highlighted some potential practical difficulties and limitations. For example, when a person with dementia is cared for in a nursing home, or the carer is not registered with the

same practice as the person with dementia. The RCGP suggested that this would result in considerable exception reporting and could significantly impact on practices covering large numbers of older people with dementia in residential homes. They also highlighted a lack of clarity in the definition of carer.

Another stakeholder commented that this indicator should apply to all carers, and that making this indicator specific to dementia would mean there is no incentive for GPs to offer support to carers of people with other conditions.

Some stakeholders also commented that the wording of the indicator should be changed to 'offered an assessment' as carers often do not want an assessment of their needs and prefer to focus on providing care for the person with dementia.

One stakeholder commented on the potential resource implications of this potential new indicator, suggesting that it represented a considerable amount of work and could become a tick box exercise. They queried who would perform the assessment, the training required to undertake the assessment and the length of time required to carry out each assessment. For practices serving populations with high prevalence of dementia, it was argued that the indicator could divert resources from other important activities.