

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

QUALITY AND OUTCOMES FRAMEWORK (QOF) INDICATOR DEVELOPMENT PROGRAMME

Briefing paper

QOF indicator area: Dementia: Care plans

Potential output: Recommendation for indicator development

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Introduction

This briefing paper presents an assessment of the suitability of measures derived from NICE quality standards, relevant to primary care, to be progressed for Quality and Outcomes Framework (QOF) indicator development. The QOF indicator area is dementia. The NICE quality standard on dementia was published in June 2010.

<http://www.nice.org.uk/guidance/qualitystandards/dementia/dementiaqualitystandard.jsp>

The relevant quality statement (statement 4) and underlying recommendation and evidence is taken from the following guidance:

National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) clinical guideline 42 '[Dementia: supporting people with dementia and their carers in health and social care](#)'

This paper is based on the recommendations presented in these guidelines and no update searches have been performed.

Topic selection

Dementia quality standard (QS1)

Quality Standards

NICE quality standards are sets of specific, concise statements and associated measures. They set out aspirational, but achievable, markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions.

Derived from the best available evidence, such as NICE guidance and other evidence sources accredited by NICE Evidence, they are developed independently by NICE in collaboration with NHS and social care professionals, their partners and service users. Quality standards address clinical effectiveness, patient safety and patient experience, and are central to supporting the government's vision for an NHS focused on delivering the best possible outcomes for patients.

Review of the dementia quality standard and identification of possible QOF indicators

The dementia quality standard was reviewed to identify potential areas for further development as QOF indicators.

Statement 4 in the dementia quality standard was considered to be an appropriate area for potential QOF indicator development:

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.

The associated process measures are:

- Proportion of people with dementia whose individual needs are assessed and whose care plan states how those needs will be addressed.
- Proportion of people with a named health or social care coordinator.

Supporting statement from the chair of the quality standard for dementia

General practitioners have a role in supporting people with dementia and their carers. While GPs may not be responsible for the implementation of a dementia care plan it is important that they are aware of the care plan and that it is reviewed at least annually. This review may form part of the face to face annual review already included in the QOF, but may also take place at other points in the year where there have been specific events or changes in disease progression in the person with dementia. GPs have an important part to play in the development of the care plan with regards to those areas that require primary care involvement, for example, the physical and mental health of people with dementia, and their carers, and the planning and provision of palliative care.

Professor Tim Kendall,

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Medical Director and consultant psychiatrist, Sheffield Health and Social Care
NHS FT

Chair of the dementia quality standard

Overview of Dementia

Epidemiological summary

Definition

Dementia is defined in the ICD-10 classification as a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capability, language and judgement. Consciousness is not impaired. Impairments of cognitive function are commonly accompanied, occasionally preceded by, deterioration in emotional control, social behaviour, or motivation. The syndrome occurs in Alzheimer's disease (AD), in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.

Incidence, prevalence and evidence of variation by age, sex and ethnicity

Dementia is an increasingly important public health issue, due to the ageing population. In the UK there are 700,000 people with dementia of whom 570,000 live in England. Dementia affects around 5% of people aged over 65, and 20% of people aged over 80. Incidence studies have shown rates of 1-3 per 1000 for people aged 65-70 rising to 14-30 per 1000 for people aged 80-85.

There are a number of conditions that cause the symptoms of dementia. AD accounts for over 50% of all cases; other common causes in older people include cerebrovascular disease (vascular dementia [VaD]) and dementia with Lewy bodies (DLB) (accounting for 15–20% of cases each).

Prevalence rates of dementia appear to vary little between countries and the condition affects all socioeconomic groups. The incidence rates of dementia vary by age and sex. Incidence is higher in men overall, but it increases at a

higher rate in women as the population ages. Ethnic differences in prevalence have not been consistently reported. The prevalence of dementia is expected to more than double in the next 30–50 years.

Morbidity and mortality

Dementia is associated with complex needs and, especially in the later stages, high levels of dependency and morbidity. Short term memory loss is common; communication difficulties, mood and personality changes occur. These needs often challenge the skills and capacity of carers and services. As the condition progresses, people with dementia can present carers and social care staff with complex problems.

Dementia is a terminal disorder, but people may live with their dementia for 7–12 years. Some evidence exists for a wide range of psychological interventions as well as a continuing search for pharmacological treatments.

Impact on health services

Primary care

The true costs of dementia in England are not known. However a report from the All-Party Parliamentary Group on Dementia (2010) estimated that in the UK, dementia cost the UK £20 billion a year of which much is spent inefficiently on poor-quality care.

Evidence suggests that there is significant under-diagnosis of dementia. A Royal College of Physicians report on the National Audit of Dementia Care in General Hospitals (2011) notes that only 40% of people with dementia currently receive a diagnosis. In a 2007 study conducted by the National Audit Office, five people per 1,000 were diagnosed with dementia at the age of 65–69 years, compared with an estimated actual prevalence of 13 per 1,000. In people over the age of 80 years, 60 of the expected 122 were diagnosed.

Secondary care

The National Audit Office report on improving dementia services in England (2010) estimated that people with dementia make up half of the total number

of people who remain in hospital unnecessarily. The Alzheimer's Society (2007) found that at any one time, up to one quarter of acute hospital beds are in use by people with dementia over the age of 65.

Current management of dementia in primary care

Dementia is often difficult to diagnose due to a variety of factors including the complex and variable ways in which cognitive impairment can present. Once a diagnosis of dementia has been made there is an important role for primary care practitioners in relation to ongoing medical management, including prescription of relevant medication and management of physical comorbidities.

Careful assessment and the development of comprehensive multidisciplinary care plans to address personal, social, medical and behavioural problems associated with dementia have become the mainstay of treatment and care programmes in the delivery of high-quality care for people with dementia and their carers.

Current QOF indicators for dementia are focused on the maintenance of a register, appropriate diagnostic testing and annual review of care.

NHS priorities and timeliness for guidance

The NICE QOF team examined national clinical guidelines, policy documents and national strategies across the UK to assess timeliness of indicators in this topic area. The following were found to be of relevance to dementia and indicate that dementia is deemed as an area of high priority for the NHS:

- NICE and SCIE (2006) Dementia: supporting people with dementia and their carers in health and social care. NICE clinical guideline 42.
- Department of Health (2009) National dementia strategy
- National Audit Office (2007) Improving services and support for people with dementia
- Scottish Intercollegiate Guidelines Network (2006) Management of patients with dementia.

- Scottish Intercollegiate Guidelines Network (2006) Assessing the mental health needs of older people. SCIE guide 3.

Review of recommendations

Summary of NICE guideline recommendations

The quality standard on dementia statement 4 was informed by the [NICE/SCIE clinical guideline 42 on dementia](#). The following recommendations from this guideline informed the basis for the development of this statement, and are therefore presented below.

To provide further context to the recommendation presented, selected recommendations from the NICE/SCIE clinical guideline 42 relating to dementia and potentially relevant to primary care are provided in appendix B.

NICE/SCIE recommendation 1.1.7.3

Care managers and care coordinators should ensure the coordinated delivery of health and social care services for people with dementia. This should involve:

- a combined care plan agreed by health and social services that takes into account the changing needs of the person with dementia and his or her carers
- assignment of named health and/or social care staff to operate the care plan
- endorsement of the care plan by the person with dementia and/or carers
- formal reviews of the care plan, at a frequency agreed between professionals involved and the person with dementia and/or carers and recorded in the notes

Evidence summary

This is a summary of the evidence supporting the recommendations from the clinical guideline presented above. This section relates to the evidence summary table in appendix A of this briefing paper.

Clinical effectiveness

NICE/SCIE recommendation 1.1.7.3

The GDG noted that there is evidence indicating that care management¹ delivers improved outcomes, for people with dementia and their carers. Care plans, their implementation and review form part of integrated care. However the GDG commented that because the models of care investigated vary, it is not possible to identify the most effective model or the individual components that contribute to their overall effectiveness. The GDG noted that people with dementia and their carers generally access mainstream services and specialist mental health services through a referral by their general practitioner or primary care team. It was of the GDG's consensus opinion that greater coordination and integration between health and social services are important for improving the delivery of support and services for people with dementia.

The GDG noted that there are a variety of disciplines with expertise in dementia care from social work to community nursing and it was of their expert opinion that these skills need to be mobilised if assessment and care coordination are to be optimised. The GDG considered that developing a generic system of case management, using locally available skills, is needed for the multidisciplinary assessment and management required for people with dementia.

Cost effectiveness

The GDG considered a study evaluating the costs and effects of care management for people with dementia, compared with fragmented community

¹ The NICE/SCIE guideline defines care management as involving four elements: the coordination of a full assessment, agreeing a care plan, arranging action to deliver services and reviewing changing needs

services. The GDG noted significant improvements in outcomes (destinational outcome, need, quality of care and quality of life) were evident by 12 months in the care management group. However, the GDG noted that due to the specialised nature of the scheme evaluated and other limitations on the transferability of the results to the wider UK setting, no firm conclusions could be drawn from the economic evidence.

Assessment of recommendations against current practice

Current practice

A GP survey by the National Audit Office (2010) found that 90% of GPs maintain a register of patients with dementia. Of those GPs, 80% report that the register prompts them to undertake regular patient reviews. Components of reviews varied widely. For example, over 50% of GPs reported assessment of physical health whilst just over 10% reported assessing social status / needs which would typically form part of a care plan.

The Health and Social Care Information Centre achievement data for QOF indicator DEM2 suggested that 73.2% of people with dementia in England had an annual review of care in 2011/12, varying from 63.7% to 83.1% between PCTs.

The GDG of the full clinical guideline for dementia noted that the organisational arrangements for needs assessment and case management of people with dementia are highly variable, with decisions about key-worker roles being decided according to local resource availability and priorities. The National Audit Office report found that 57% of GPs are still unaware of a local care pathway to guide them in diagnosing and managing dementia. Indicators for care plans in people with dementia would help to improve care for people with dementia standardising assessments and leading to improved coordination of care.

Health inequalities

There is evidence that dementia is more prevalent in older age groups however no evidence was presented in the NICE/SCIE guideline that

suggests the recommendation presented in this briefing paper can directly impact health inequalities. [Relevance to health inequalities: Moderate]

Will implementation of these recommendations lead to cost-effective improvements in the delivery of primary care?

There is no evidence presented in the NICE/SCIE clinical guideline for dementia to suggest care plans for people with COPD can directly lead to cost effective improvements in the delivery of primary care.

Initial feasibility assessment

Indicators for care plans already exist in the QOF e.g. for people with mental health and these are shown to be feasible. Consideration may need to be given as to what constitutes a care plan and the minimum content required for achievement of indicators. In addition the need to capture individual components of a care plan (or whether this would be better as indicator guidance) would need to be determined in order to develop indicator(s) to best describe care.

The timeframe in which the care plan should be undertaken following entry onto the register would need to be considered, and also whether this should be measured prospectively or form part of the existing face to face annual in the QOF.

Potential shared care responsibilities may need to be considered and how this should be translated into an indicator which is attributable to primary care.

Key considerations

The following key considerations summarise the main points made in this briefing paper to support the Committee in its discussions.

- Indicators on care planning are under consideration of the Committee for people with COPD, end of life care and diabetes.
- An annual face to face care review is already included in the QOF for people with dementia under current QOF indicator DEM002. While GPs may not be responsible for the implantation of a dementia care plan it is

important that they are aware of the care plan and that it is reviewed at least annually. This review may form part of the face to face annual review already included in the QOF.

Assessment against NICE's prioritisation criteria

The condition is considered to have a population prevalence that is high; it partly meets the criteria for diagnosis, treatment and monitoring in primary care (by general practitioners or directly employed practice staff).

The recommendations selected are considered feasible. The evidence of clinical effectiveness is based on the expert opinion of the GDG and no evidence of cost effectiveness if available. The expected change in practice is considered to be moderate.

References

All-Party Parliamentary Group on Dementia (2010). The £20 Billion Question: An inquiry into improving lives through cost-effective dementia services. Alzheimer's Society, London.

Alzheimer's Society (2007). Dementia UK: The full report. Alzheimer's Society, London.

National Audit Office (2010) [Improving dementia services in England - an interim report](#)

NHS Information Centre (2011) QOF 2011/12 results: England level QOF tables 2011/12 – clinical tables 2011/12 [online]. Available from www.qof.ic.nhs.uk

Department of Health (2009) National dementia strategy.

Appendix A: Evidence summary

Evidence Summary of NICE clinical guideline 42 selected recommendations

	Recommendation	Level of evidence	Key outcomes considered	Specific considerations highlighted by guideline developers	Cost-effectiveness evidence
Dementia: Care plans					
Recommendation 1.1.7.3	<p>Care managers and care coordinators should ensure the coordinated delivery of health and social care services for people with dementia. This should involve:</p> <ul style="list-style-type: none"> • a combined care plan agreed by health and social services that takes into account the changing needs of the person with dementia and his or her carers • assignment of named health 	GDG expert opinion	N/A	<p>The GDG noted evidence from a UK study of care management for people with dementia which found care management to deliver better outcomes than standard community old age mental healthcare.</p> <p>At 6 months, people with dementia served by an intensive care management team were more satisfied with their home environment and had more improvement in social contact in comparison with those served by standard community old age services (both findings were statistically significant). At one year, the care management group continued to show significant improvement in social contact, in contrast to those receiving standard care.</p> <p>The authors noted that the positive outcomes observed appeared attributable to care management. The GDG noted that although this study describes a model of a specialist integrated dementia care service in the UK, it does not provide evidence on the effectiveness of integrated health and social care services, as care was provided by an integrated team to both the</p>	<p>The GDG considered evidence from a UK cost-consequences analysis of care management for people with dementia (Challis et al, 2002). This evaluated the costs and effects of care management for people with dementia, compared with fragmented community services.</p> <p>The outcomes measured were destination outcome, need, quality of care and quality of life of both the person with dementia and his or her carer, presented alongside the annual costs.</p> <p>The costs included in</p>

	Recommendation	Level of evidence	Key outcomes considered	Specific considerations highlighted by guideline developers	Cost-effectiveness evidence
Dementia: Care plans					
	<p>and/or social care staff to operate the care plan</p> <ul style="list-style-type: none"> • endorsement of the care plan by the person with dementia and/or carers • formal reviews of the care plan, at a frequency agreed between professionals involved and the person with dementia and/or carers and recorded in the notes 			<p>intervention and control groups.</p> <p>The GDG noted that neither the systematic literature search nor the review of qualitative evidence identified evidence on the impact of integrated services on health and quality of life outcomes for people with dementia or their carers. However the GDG considered two studies that address the impact of integrated services on outcomes for older people in the UK.</p> <p>The first study by Brown and colleagues (2003) found that the response from referral to assessment was quicker in integrated health and social care teams compared to teams with more traditional arrangements. The authors speculated that an integrated one-stop shop approach and better communication, understanding and exchange of information amongst different professional groups may have had an impact on the process of service delivery, with improvements in the initial stages of the process of seeking help and being assessed for a service.</p> <p>The second study by Davey and colleagues (2005) compared the effectiveness of two different models of integration on outcomes for older people and concluded that</p>	<p>the analysis were for long-term care, community care services, hospital and GP care, professional visits (which include care managers), as well as out-of-pocket expenses, housing and care provided by family carers.</p> <p>Significant differences in outcomes between interventions were evident by 12 months. Specifically, the care management group improved and maintained social contact, and carers experienced less burden and stress, a reduction in workload and an improved level of support. The care management group also experienced a</p>

	Recommendation	Level of evidence	Key outcomes considered	Specific considerations highlighted by guideline developers	Cost-effectiveness evidence
Dementia: Care plans					
				<p>outcomes are affected by a number of factors, one of which is cognitive function. The study suggested that it is difficult to demonstrate the effects of services or the way they are organised.</p> <p>The GDG noted that the evidence base for recommendations on the planning and organization of services for people with dementia and their carers is small (or non-existent in relation to some services) and generally of a poor quality or not easily applicable to the UK, therefore service recommendations are largely based on good practice using the Department of Health's <i>Because Everybody's Business</i> service development Guide.</p>	<p>greater proportion of people with dementia remaining in their own home in the long term. The authors noted that although the mean annual costs for care management were higher some of the increased costs were offset by lower costs incurred by carers.</p> <p>Nevertheless the GDG considered that no firm conclusions could be drawn due to the specialised nature of the scheme evaluated and other limitations on the transferability of the results to the wider UK setting.</p>

Appendix B: Selected recommendations from the NICE/SCIE clinical guideline 42 relating dementia potentially relevant to primary care

The recommendations highlighted in grey are included in the main part of the briefing paper for consideration for indicator development.

Principles of care for people with dementia

Recommendation 1.1.1.3

Health and social care staff should identify the specific needs of people with dementia and their carers arising from diversity, including gender, ethnicity, age (younger or older), religion and personal care. Care plans should record and address these needs.

Recommendation 1.1.1.4

Health and social care staff should identify the specific needs of people with dementia and their carers arising from ill health, physical disability, sensory impairment, communication difficulties, problems with nutrition, poor oral health and learning disabilities. Care plans should record and address these needs.

Recommendation 1.1.1.5

Health and social care staff, especially in residential settings, should identify and, wherever possible, accommodate the preferences of people with dementia and their carers, including diet, sexuality and religion. Care plans should record and address these preferences.

Ethics, consent and advance decision making

Recommendation 1.1.4.4

Health and social care professionals should discuss with the person with dementia, while he or she still has capacity, and his or her carer the use of:

- advance statements (which allow people to state what is to be done if they should subsequently lose the capacity to decide or to communicate)
- advance decisions to refuse treatment
- Lasting Power of Attorney (a legal document that allows people to state in writing who they want to make certain decisions for them if they cannot make them for themselves, including decisions about personal health and welfare)
- a Preferred Place of Care Plan (which allows people to record decisions about future care choices and the place where the person would like to die).

Management and coordination of care

Recommendation 1.1.7.1

Health and social care staff should ensure that care of people with dementia and support for their carers is planned and provided within the framework of care management/coordination

Recommendation 1.1.7.2

Care managers and care coordinators should ensure that care plans are based on an assessment of the person with dementia's life history, social and family circumstance, and preferences, as well as their physical and mental health needs and current level of functioning and abilities.

Recommendation 1.1.7.3

Care managers and care coordinators should ensure the coordinated delivery of health and social care services for people with dementia. This should involve:

- a combined care plan agreed by health and social services that takes into account the changing needs of the person with dementia and his or her carers

- assignment of named health and/or social care staff to operate the care plan
- endorsement of the care plan by the person with dementia and/or carers
- formal reviews of the care plan, at a frequency agreed between professionals involved and the person with dementia and/or carers and recorded in the notes

Promoting and maintaining independence of people with dementia

Recommendation 1.5.1.1

Health and social care staff should aim to promote and maintain the independence, including mobility, of people with dementia. Care plans should address activities of daily living (ADLs) that maximise independent activity, enhance function, adapt and develop skills, and minimise the need for support. When writing care plans, the varying needs of people with different types of dementia should be addressed. Care plans should always include:

- consistent and stable staffing
- retaining a familiar environment
- minimising relocations
- flexibility to accommodate fluctuating abilities
- assessment and care-planning advice regarding ADLs, and ADL skill training from an occupational therapist
- assessment and care-planning advice about independent toileting skills; if incontinence occurs all possible causes should be assessed and relevant treatments tried before concluding that it is permanent
- environmental modifications to aid independent functioning, including assistive technology, with advice from an occupational therapist and/or clinical psychologist
- physical exercise, with assessment and advice from a physiotherapist when needed
- support for people to go at their own pace and participate in activities they enjoy.

Appendix C: Related QOF indicators

Related existing QOF indicators from 2013/14 indicator set

Dementia is part of the existing QOF clinical domain as defined in the 2013/14 GMS Contract guidance. QOF indicators for England for this domain are outlined below. Indicators for Scotland, Wales and Ireland can be found from the relevant countries web pages.

QOF domain 2013/14: Dementia

Indicator	Points	Achievement thresholds
Records		
DEM001. The contractor establishes and maintains a register of patients diagnosed with dementia	5	
Ongoing Management		
DEM002. The percentage of patients diagnosed with dementia whose care has been reviewed in a face-to-face review in the preceding 12 months	15	35-70%
DEM003. The percentage of patients with a new diagnosis of dementia recorded in the preceding 1 April to 31 March with a record of FBC, calcium, glucose, renal and liver function, thyroid function tests, serum vitamin B12 and folate levels recorded between 6 months before or after entering on to the register	6	45-80%

Related indicators from the NICE menu of indicators

All dementia related indicators on the NICE menu have been negotiated into the 2013/14 QOF and listed above.

Related indicators under consideration by the Advisory Committee

The committee is asked to consider the briefing paper on dementia memory assessment. The committee is also asked to consider briefing papers relating to care plans for people in end of life care, and with diabetes and COPD.

Appendix D: Assessment of topic and recommendations against prioritisation checklist criteria status

The overall topic and recommendation(s) produced by the QOF programme team have been assessed by comparing information in this briefing paper with the revised prioritisation checklist as agreed at the July 2009 Advisory Committee meeting.

Topic status

This topic meets the prioritisation criteria for prevalence, primary care management and disease severity as outlined in 1A, 1B and 1C below.

1A Population	
The condition is considered to have population prevalence that is high	<input checked="" type="checkbox"/>
The condition is considered to have population prevalence that is medium	<input type="checkbox"/>
The condition is considered to have population prevalence that is low	<input type="checkbox"/>

1B Management			
	Fully meets criteria	Partly meets criteria	Doesn't meet criteria
Score:	[3]	[2]	[1]
The condition is diagnosed in primary care*	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
The condition is treated in primary care*	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The condition is monitored in primary care*	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>* by general practitioners or directly employed practice staff</i>			

1C Disease Severity		
Score	Scoring criteria	
1	Minor quality-of-life impact, no disability, limited morbidity impact	<input type="checkbox"/>
2	Definite quality-of-life impact, no disability, limited morbidity impact	<input type="checkbox"/>
3	Definite quality-of-life impact, some disability and/or intermediate morbidity impact	<input type="checkbox"/>
4	Definite quality-of-life impact, significant disability and/or significant morbidity impact	<input checked="" type="checkbox"/>

Recommendation status

The individual recommendations are assessed on feasibility, strength of clinical and cost-effectiveness evidence and expected change in practice.

Feasibility of each recommendation	
Dementia Care	
Recommendation 1.1.7.3	Green

Scores for each recommendation			
	Evidence of clinical effectiveness	Evidence of cost effectiveness	Expected change in practice
Dementia Care			
Recommendation 1.1.7.3	Low	Moderate	Moderate