NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

IMPLEMENTATION DIRECTORATE

QUALITY STANDARDS PROGRAMME

Quality standard topic: Dementia

Output: Quality Standard advice to the Secretary of State for Health

Scope:
Care provided by health and social care staff in direct contact with people with dementia in hospital, community, home-based, group care, residential or specialist care settings.

Policy context:
National Audit Office, 'Improving dementia services in England: an Interim report' (2010).
Department of Health, 'The use of antipsychotic medication for people with dementia: Time for action' (2009).
Department of Health, 'Living well with dementia: a national dementia strategy' (2009).
National Audit Office, 'Improving services and support for people with dementia' (2007).

Key development sources:
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' (2006; NHS Evidence accredited).

Overview of statements:
The 11 key priorities for implementation from the NICE-SCIE clinical guideline 42 (CG42) were developed by the Topic Expert Group (TEG) into 10 draft quality statements. Of the remaining 115 recommendations, 12 were discussed further and resulted in 8 additional draft quality statements. A total of 18 draft quality statements were presented for consultation, each with associated quality measures. Following consultation and field testing feedback, the TEG prioritised 10 statements for inclusion into the final quality standard.

Further explanation of the methodology used can be found in the Quality Standards Programme interim process guide.

Quality measures:
The quality measures accompanying the quality standard are intended to improve the structure, process and outcomes of health and social care. They are not a new set of targets or mandated indicators for performance management. Quality measures are worded as high level quality indicators. Furthermore, the quality measures may be supplemented with indicators developed by the NHS Information Centre through their Indicators for Quality Improvement Programme. If such quality indicators do not currently exist it is intended that the quality measures should form the basis for audit criteria developed and used locally to improve the quality of healthcare. It is also noted that at present there are limited health

outcome measures that can be used as quality measures: the focus of the quality measures is on improving health outcomes through improving processes of care that are considered to be linked to health outcomes. However, consideration should be given to using DEM-QOL to assess the health-related quality of life of people with dementia.

All quality measures are specified in the form of a numerator and a denominator, which define a proportion (numerator/denominator). It is assumed that the numerator is a subset of the denominator population.

For example, if the quality measure is:
Numerator – the number carers offered an assessment of their needs
Denominator – the number of carers of people with dementia.

The correct proportion is the number of carers of people with dementia who are offered an assessment of their needs. The numerator **does not** include carers whose needs are assessed but **who are not** carers of people with dementia.

Diversity, equality and language

Good communication between health and social care professionals and people with dementia is essential. Treatment and care, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. People with dementia should have access to an interpreter or advocate if needed.

Quality standard for dementia

The quality standard for dementia requires that dementia services should be commissioned from and coordinated across all relevant agencies encompassing the whole dementia care pathway. An integrated approach to provision of services is fundamental to the delivery of high quality care to people with dementia.

Number	**Quality statements**
1	People with dementia receive care from staff appropriately trained in dementia care.
2	People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.
3	People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.
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.
5	People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of : • advance statements • advance decisions to refuse treatment • Lasting Power of Attorney • Preferred Priorities of Care.
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.
7	People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.
8	People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.
9	People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.
10	Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.

Quality standard for dementia

Quality statement 1

Quality statement	People with dementia receive care from staff appropriately trained in dementia care.
Quality measure	**Structure**: Evidence of local arrangements to provide and maintain up to date dementia training for staff. **Process**: Proportion of staff working with people with dementia who have dementia care training Numerator – the number of staff who are trained in dementia care. Denominator – the number of staff working with people with dementia.
Description of what the quality statement means for each audience	**Service providers** ensure that all health and social care workers are appropriately trained in dementia care according to their roles and responsibilities. **Health and social care professionals** who work with people with dementia ensure they receive training in dementia care consistent with their roles and responsibilities. **Commissioners** ensure service providers have arrangements for training health and social care professionals in dementia care. **People with dementia** can expect that the health and social care professionals who care for them will have dementia care training.
Data source	**Structure**: Local data collection. Contained within NICE CG42 audit support, criterion 9. Acute Trusts can collect data on dementia awareness training using the National Audit of Dementia organisational checklist, section 7. **Process**: Local data collection.

Quality statement 2

Quality statement	People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.
Quality measure	**Structure:** Evidence that memory assessment services specialising in the diagnosis and initial management of dementia are the single point of referral for people with a possible diagnosis of dementia. **Process:** Proportion of people with suspected dementia who are referred to a memory assessment service specialising in the diagnosis and initial management of dementia. Numerator – the number of people who are referred to a memory assessment service specialising in the diagnosis and initial management of dementia. Denominator – the number of people with suspected dementia.
Description of what the quality statement means for each audience	**Service providers** ensure they offer a full range of services to aid diagnosis and initial management of dementia **Health and social care professionals** working with those with a possible diagnosis of dementia are aware of the process by which referrals can be made to the local memory assessment service. **Commissioners** ensure all referrers can access memory assessment services for people with a possible diagnosis of dementia. **People receiving a possible diagnosis of dementia** can expect to be referred to a memory assessment service.
Data source	**Structure:** Local data collection. **Process:** Local data collection. Contained within NICE CG42 audit support, criterion 5.

Quality statement 3

Quality statement	People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.
Quality measure	**Structure:** Evidence of local arrangements to ensure written information on dementia is available to staff. **Process:** Proportion of people newly diagnosed with dementia receiving written and verbal information about their condition, treatment and the support options in their local area. Numerator – the number of people receiving written and verbal information about their condition, treatment and the support options in the local area. Denominator – the number of people newly diagnosed with dementia.
Description of what the quality statement means for each audience	**Service providers** ensure that written information about dementia, treatment and local area support options is available to staff. **Health and social care professionals** provide written and verbal information about dementia, treatment and local area support options once a diagnosis of dementia is established. **Commissioners** ensure that services make available written information about dementia, treatment and local area support options. **People newly diagnosed with dementia** can expect to be provided with written and verbal information about their condition, treatment and the support options in their local area.
Definitions	Written information for patients can be found in the Department of Health 'Who cares?' booklet. Information about NICE guidance, written specifically for patients can be found in 'Dementia: Understanding NICE guidance' (NICE clinical guideline 42, 2006).
Data source	**Structure:** Local data collection. Acute Trusts, Primary Care Trusts and Mental Health Trusts can demonstrate processes for developing written information via NHS Litigation Authority Risk Management Standards 4, criterion 2. **Process:** Local data collection.

Quality statement 4

Quality statement	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 measure	**Structure:** Evidence of local arrangements to ensure services are tailored to an individual's needs. **Process:** a) Proportion of people with dementia whose individual needs are assessed and whose care plan states how those needs will be addressed. Numerator: Number of people with an assessment of individual needs and a care plan addressing identified needs. Denominator: Number of people with dementia b) Proportion of people with a named health or social care coordinator. Numerator – the number of people with a named health or social care coordinator. Denominator – the number of people with dementia.
Description of what the quality statement means for each audience	**Service providers** ensure that protocols are in place to ensure that personalised care plans identify named care coordinators and address the individual needs of people with dementia. **Health and social care professionals** ensure that personalised care plans identify a named care coordinator and address the individual needs of the person with dementia. **Commissioners** ensure that services are commissioned that tailor interventions to the individual needs of a person with dementia. **People with dementia** can expect to receive a care plan that identifies a named care coordinator and addresses their individual needs.

Definitions	'Individual needs' arise from: • Diversity, including gender, ethnicity, age (younger or older), religion and personal care. • Ill health, physical disability, sensory impairment, communication difficulties, problems with nutrition, poor oral health and learning disabilities. • The life story and preferences of people with dementia and their carer/s (where possible) including diet, sexuality and religion. • Maintaining independence. • Information needs.
Data source	**Structure:** Local data collection. **Process:** a) Local data collection. Acute Trusts can collect data on the content of assessments using the National Audit of Dementia casenote audit, section 2. b) Local data collection. Contained within NICE CG42 audit support, criterion 6.

Quality statement 5

Quality statement	People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of : • advance statements • advance decisions to refuse treatment • Lasting Power of Attorney • Preferred Priorities of Care.
Quality measure	**Structure**: Evidence of local protocols on the discussion of advance decision making. **Process**: Proportion of people with dementia, while they have capacity, and their carer/s, who are given the opportunity to discuss with health and social care professionals about the use of: • advance statements • advance decisions to refuse treatment • Lasting Power of Attorney • Preferred Priorities of Care. Numerator – the number of people who are given the opportunity to discuss advance decision making. Denominator – the number of people with dementia. Numerator – the number of carers who are given the opportunity to discuss advance decision making. Denominator – the number of carers of people with dementia.
Description of what the quality statement means for each audience	**Service providers** ensure staff are appropriately trained to provide information on advance statements, advance decisions to refuse treatment, Lasting Power of Attorney and Preferred Priorities of Care. **Health and social care professionals** offer the person with dementia, whilst they have capacity, the opportunity to discuss and make decisions together with their carer/s about the use of: • advance statements • advance decisions to refuse treatment • Lasting Power of Attorney • Preferred Priorities of Care. **Commissioners** ensure that local arrangements for assessment and care planning specifically include advance decision making. **People with dementia** and their carers can expect the opportunity to discuss and make a decision on the use of advance statements, advance decisions to refuse treatment, Lasting Power of Attorney and Preferred Priorities of Care.

Data source	**Structure**: Local data collection. **Process**: Local data collection.

Quality statement 6

Quality statement	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.
Quality measure	**Structure**: • Evidence that those carrying out a carers' assessment identify any emotional and psychological needs and the social impact on the carer and offer the carer psychological therapy, including cognitive behavioural therapy (CBT), if clinically appropriate. • Evidence that this is an ongoing process and includes any period after the person with dementia has entered residential care. • Evidence that care plans for carers of people with dementia involve a range of tailored interventions, which consist of multiple components including: – individual or group psychoeducation – peer-support groups with other carers, tailored to the needs of individuals depending on the stage of dementia of the person being cared for and other characteristics. **Process:** a) Proportion of carers of people with dementia who are offered an assessment of their needs. Numerator – the number of carers offered an assessment of their needs. Denominator – the number of carers of people with dementia. b) Proportion of carers of people with dementia receiving interventions tailored to their needs. Numerator – the number of carers receiving interventions tailored to their needs Denominator – the number of carers of people with dementia who have an agreed care plan.

Description of what the quality statement means for each audience	**Service providers** ensure that carers of people with dementia are offered an assessment of needs and receive tailored interventions to address any identified. **Health and social care professionals** ensure that carers accepting an assessment of their needs receive a care plan containing a range of tailored interventions including • Psychological therapy including CBT. • Psychoeducational programmes. • Peer support. **Commissioners** ensure services offer a range of tailored interventions. **Carers** of people with dementia can expect to be offered an assessment of their needs and tailored interventions to address any needs that are identified.
Data source	**Structure:** Local data collection. **Process:** Local data collection. Contained within NICE CG42 audit support, criterion 3.

Quality statement 7

<table>
<tr><td>Quality statement</td><td>People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.</td></tr>
<tr><td>Quality measure</td><td>Structure:
a) Evidence that people with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity.
b) Evidence that individually tailored care plans, that help carers and staff address the behaviour that challenges, are recorded in the notes and reviewed regularly.

Process:
a) Proportion of people with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, who receive an assessment to establish likely factors that may generate, aggravate or improve such distress or behaviour.
Numerator – the number of people who receive an assessment.
Denominator – the number of people with dementia who develop non-cognitive symptoms that cause them significant distress or who develop behaviour that challenges.

b) Proportion of people with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, with an individualised care plan identifying actions to address the distress or behaviour.
Numerator – the number of people with an individualised care plan identifying actions to address the distress or behaviour.
Denominator – the number of people with dementia who develop non-cognitive symptoms that cause them significant distress or who develop behaviour that challenges.

c) Proportion of people with dementia with mild-to-moderate non-cognitive symptoms who are prescribed anti-psychotic medication. (Goal to be 0% reflecting the Department of Health report on the use of anti-psychotic medication for people with dementia and its aim to reduce the use of anti-psychotic medication for people with dementia.)
Numerator – the number of people prescribed anti-psychotic medication.
Denominator – the number of people with dementia with mild-to-moderate non-cognitive symptoms.</td></tr>
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Description of what the quality statement means for each audience	**Service providers** ensure that all people with dementia who develop non-cognitive symptoms that cause significant distress, or who develop behaviour that challenges, are given a comprehensive assessment. **Health and social care professionals** working with people with dementia who develop non-cognitive symptoms carry out a comprehensive assessment. A behavioural and functional analysis should be conducted by health and social care professionals with specific skills, in conjunction with carers and care workers, and an individually tailored care plan should be developed to address the issues. **Commissioners** ensure local service providers are adequately resourced and trained to undertake comprehensive assessment and management of people with non-cognitive symptoms of dementia. **People with dementia** who develop non-cognitive symptoms that cause them significant distress or who develop behaviour that challenges can expect to be offered a comprehensive assessment at an early stage.
Definitions	The assessment must include: • the person's physical health • depression • possible undetected pain or discomfort • side effects of medication • individual biography, including religious beliefs and spiritual and cultural identity • psychosocial factors • physical environmental factors • behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers.
Data source	**Structure:** Local data collection. **Process:** a) and b) Local data collection. Contained within NICE CG42 audit support, criterion 8. c) Local data collection. Acute Trusts can collect data on the main recorded reason for any prescription of antipsychotic medication using the National Audit of Dementia casenote audit, section 2 (however, the audit is not specific to people with mild-to-moderate non-cognitive symptoms).

Quality statement 8

Quality statement	People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.
Quality measure	**Structure:** Evidence of local arrangements to provide a liaison service specialising in the diagnosis and management of dementia and older people's mental health. **Process:** Proportion of people with suspected or known dementia using acute and general hospital facilities that are assessed by a liaison service that specialises in the diagnosis and management of dementia and older people's mental health. Numerator – the number of people who are assessed by a liaison service that specialises in the diagnosis and management of dementia and older people's mental health. Denominator – the number of people with suspected or known dementia who are admitted to acute or general hospital inpatient services or attending emergency departments.
Description of what the quality statement means for each audience	**Service providers** ensure that a liaison service specialising in dementia and older people's mental health is available in acute and general hospital settings to assess inpatients and emergency department attendances with suspected or confirmed dementia. **Health care professionals** working in acute and general hospital settings ensure they can access a liaison team that specialises in the diagnosis and management of dementia and older people's mental health. **Commissioners** ensure provision of a liaison service specialising in dementia and older people's mental health to work across acute and general hospital settings to assess people with suspected or known dementia. **People with suspected or known dementia** admitted to acute and general hospital settings or attending emergency departments can expect, if clinically appropriate, to receive an assessment by a liaison service specialising in dementia and older people's mental health.
Definitions	Local commissioning arrangements should decide the activity levels for the liaison service.

Data source	**Structure:** Local data collection. Acute Trusts can collect data on the composition of liaison teams using the National Audit of Dementia organisational checklist, section 9. **Process:** Local data collection. Acute Trusts can collect data on referrals to liaison teams using the National Audit of Dementia casenote audit, section 4.

Quality statement 9

Quality statement	People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.
Quality measure	**Structure:** Evidence of local arrangements for primary care teams to assess the palliative care needs of people in the later stages of dementia. **Process:** Proportion of people in the later stages of dementia whose palliative care needs are assessed by primary care teams and the resulting information is communicated within the team and with other health and social care staff. Numerator – the number of people whose palliative care needs are assessed by a primary care team and communicated within the team and with other health and social care staff. Denominator – the number of people in the later stages of dementia.
Description of what the quality statement means for each audience	**Service providers** ensure that all people in the later stages of dementia have their palliative care needs assessed by primary care teams and that the needs are communicated to other health and social care staff. **Health and social care professionals** ensure that people who are in the later stages of dementia have their palliative care needs met in accordance with the DH's End of Life Care Strategy. This includes use of appropriate tools and pathways including: • Preferred priorities of care. • Gold Standards Framework. • Liverpool Care Pathway. **Commissioners** ensure primary care teams are resourced and trained to provide palliative care for people with dementia. **People in the later stages of dementia** can expect their palliative care needs to be assessed by their primary care team and for the results to be communicated to relevant staff.
Definitions	Later stages of dementia can be defined as those with an established diagnosis of moderate or more severe dementia.
Data source	**Structure:** Local data collection **Process:** Local data collection

Quality statement 10

Quality statement	Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.
Quality measure	**Structure:** Evidence that health and social care managers ensure that carers of people with dementia have access to a comprehensive range of respite/short-break services which meet the needs of both the carer and the person with dementia. **Process:** Proportion of carers of people with dementia who access respite/short-break services when required. Numerator – the number of carers accessing respite/short-break services. Denominator – the number of carers of people with dementia requesting respite/short-break services.
Description of what the quality statement means for each audience	**Service providers** ensure that information is available to health and social care staff on the range of respite/short-break services available to carers of people with dementia. **Health and social care professionals** ensure that carers of people with dementia are aware of the options available to them locally for respite/short-break services, and that access to such services is facilitated when needed. **Commissioners** ensure a comprehensive range of local respite/short-break services are accessible and meet the needs of both carers and people with dementia. **Carers** of people with dementia can expect to have access to a range of respite/short-break services which meet their needs.
Data source	**Structure:** Local data collection. **Process:** Local data collection.