

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Dementia

NICE quality standard

Draft for consultation

29 January 2019

This quality standard covers preventing dementia, and assessment, management and health and social care support for adults with dementia. It describes high-quality care in priority areas for improvement.

It is for commissioners, service providers, health, public health and social care practitioners, and the public.

This quality standard will update the existing quality standards on [dementia: support in health and social care](#) (published June 2010) and [dementia: independence and wellbeing](#) (published April 2013). For more information see [update information](#)

This is the draft quality standard for consultation (from 29 January to 26 February 2019). The final quality standard is expected to publish in June 2019.

Quality statements

[Statement 1](#) Adults accessing behaviour change interventions and programmes are informed that the risk of developing dementia can be reduced by making lifestyle changes. **[new 2019]**

[Statement 2](#) Adults with suspected dementia are referred to a specialist dementia diagnostic service. **[2010, updated 2019]**

[Statement 3](#) Adults with dementia have a named care coordinator. **[2010, updated 2019]**

[Statement 4](#) Adults with dementia are given a choice of activities to promote wellbeing that are tailored to their preferences. **[2013, updated 2019]**

[Statement 5](#) Adults with dementia have a structured assessment before starting non-pharmacological or pharmacological treatment for distress. **[2010, updated 2019]**

[Statement 6](#) Adults with dementia have the opportunity to discuss advance care planning at diagnosis and at each care review. **[2010, updated 2019]**

[Statement 7](#) Carers of adults with dementia are offered education and skills training. **[2010, updated 2019]**

In 2019 this quality standard was updated and statements prioritised in 2010 and 2013 were updated [2010 or 2013, updated 2019] or replaced [new 2019]. For more information, see [update information](#).

Statements from the 2010 quality standard for dementia: support in health and social care that may still be useful at a local level, but are no longer considered national priorities for improvement:

- People with dementia receive care from staff appropriately trained in dementia care.

- 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.
- 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.
- People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.
- 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.

Statements from the 2013 quality standard for dementia: independence and wellbeing that may still be useful at a local level, but are no longer considered national priorities for improvement:

- People worried about possible dementia in themselves or someone they know can discuss their concerns, and the options of seeking a diagnosis, with someone with knowledge and expertise.
- People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.
- People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change.
- People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.
- People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.
- People with dementia live in housing that meets their specific needs.
- People with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.
- People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.

- People with dementia are enabled, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community.

The [2010 quality standard for dementia: support in health and social care](#) and the [2013 quality standard for dementia: independence and wellbeing](#) are available as a pdf.

NICE has developed guidance and a quality standard on patient experience in adult NHS services and service user experience in adult mental health services (see the NICE pathway on [patient experience in adult NHS services](#) and [service user experience in adult mental health services](#)), which should be considered alongside these quality statements.

Other quality standards that should be considered when commissioning or providing dementia services include:

- [Medicines management for people receiving social care in the community](#) (2018) NICE quality standard 171
- [Care of dying adults in the last days of life](#) (2017) NICE quality standard 144
- [End of life care for adults](#) (2017) NICE quality standard 13
- [Mental wellbeing and independence for older people](#) (2016) NICE quality standard 137
- [Transition between inpatient hospital settings and community or care home settings for adults with social care needs](#) (2016) NICE quality standard 136
- [Social care for older people with multiple long-term conditions](#) (2016) NICE quality standard 132
- [Home care for older people](#) (2016) NICE quality standard 123
- [Medicines management in care homes](#) (2015) NICE quality standard 85
- [Mental wellbeing of older people in care homes \(2013\)](#) NICE quality standard 50

A full list of NICE quality standards is available from the [quality standards topic library](#).

Questions for consultation

Questions about the quality standard

Question 1 Does this draft quality standard accurately reflect the key areas for quality improvement?

Question 2 Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place?

Question 3 Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Local practice case studies

Question 4 Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to [NICE local practice case studies](#) on the NICE website. Examples of using NICE quality standards can also be submitted.

Quality statement 1: Prevention – health promotion interventions

Quality statement

Adults accessing behaviour change interventions and programmes are informed that the risk of developing dementia can be reduced by making lifestyle changes. **[new 2019]**

Rationale

There is limited awareness among both the public and practitioners that the risk of developing some types of dementia can be reduced, or the onset or progression delayed, through lifestyle changes. Making this clear in interventions and programmes that promote behaviour change, such as NHS Health Checks and stop smoking services, should encourage changes in unhealthy behaviour, which could lead to fewer people developing dementia.

Quality measures

Structure

a) Evidence that service specifications for behaviour change interventions and programmes include actions to raise awareness of lifestyle changes that could reduce the risk of developing dementia.

Data source: Local data collection, for example, local service specifications.

b) Evidence that training for practitioners delivering behaviour change interventions and programmes includes how to advise and support people to change behaviour to reduce the risk of developing dementia.

Data source: Local data collection, for example, local service specifications.

c) Evidence that information about the link between unhealthy behaviours and the risk of developing dementia is included in local health promotion materials.

Data source: Local data collection, for example, local health promotion leaflets or websites.

Process

Proportion of adults accessing behaviour change interventions and programmes who are told that the risk of developing dementia can be reduced by making lifestyle changes.

Numerator –the number in the denominator who are told that the risk of developing dementia can be reduced by making lifestyle changes.

Denominator – the number of adults accessing behaviour change interventions and programmes.

Data source: Local data collection, for example, local audit of patient records.

Outcomes

a) Public awareness of the link between dementia and lifestyle.

Data source: Local data collection, for example, public surveys.

b) Uptake of healthy lifestyle behaviours.

Data source: Local data collection, for example, public surveys. The Public Health England [Public Health Outcomes Framework data](#) includes data on portions of fruit and vegetables consumed, physical activity, smoking prevalence, alcohol-related admissions and social isolation of adult social care users. Public Health England also has [national profiles](#) on physical activity, alcohol and tobacco control.

What the quality statement means for different audiences

Service providers (such as stop smoking services, leisure services, NHS Health Checks and other health and wellbeing service providers) ensure that staff delivering behaviour change interventions and programmes are aware of lifestyle changes that can reduce the risk of developing dementia, and offer advice on reducing this risk.

Health and public health practitioners (such as health improvement practitioners, health trainers, GPs, nurses and stop smoking advisers) are aware of the lifestyle changes that can reduce the risk of developing dementia and offer advice on reducing this risk.

Commissioners (such as clinical commissioning groups and local authorities) ensure that service specifications for behaviour change interventions and programmes include the lifestyle changes that can reduce the risk of developing dementia and the actions needed to raise awareness of this. They ensure that services delivering these interventions and programmes offer advice on reducing the risk of dementia.

Adults having NHS Health Checks or taking part in health and wellbeing programmes are told about lifestyle changes they can make to reduce their risk of developing dementia.

Source guidance

[Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset](#) (2015) NICE guideline NG16, recommendations 2, 4 and 9

Definitions of terms used in this quality statement

Lifestyle changes

Behaviours such as smoking, lack of physical activity, unhealthy diet, alcohol consumption, being overweight or obese and loneliness that can be changed to reduce the risk of developing dementia. [NICE's guideline on [dementia, disability and frailty in later life](#), recommendation 3]

Equality and diversity considerations

People should be provided with information about the risk factors for dementia that they can easily read and understand themselves, or with support. Information should be in a format that suits their needs and preferences. It should be accessible to people who do not speak or read English, and it should be culturally appropriate and age appropriate.

Quality statement 2: Diagnosis

Quality statement

Adults with suspected dementia are referred to a specialist dementia diagnostic service. [2010, updated 2019]

Rationale

Involving dementia specialist diagnostic services ensures that diagnosis is timely and accurate, and that people can access appropriate support and treatment sooner. The benefits of a timely diagnosis include early consideration of mental capacity and advance care planning, knowing what to expect, and enabling families and carers to make plans.

Quality measures

Structure

Evidence of local referral criteria and pathways to ensure that adults with suspected dementia are referred to a specialist dementia diagnostic service.

Data source: Local data collection, for example, local commissioning agreements and service specifications.

Process

Proportion of adults with dementia who have a record of attending a specialist dementia diagnostic service up to 12 months before entering on to the register.

Numerator –the number in the denominator who were referred to a specialist dementia diagnostic service up to 12 months before entering on to the GP practice register.

Denominator – the number of adults with dementia on the GP practice register.

Data source: Local data collection. An indicator was piloted and shown to be feasible by the NICE indicator programme. See NICE indicator [NM65](#).

Outcome

Self-reported or carer-reported quality of life of adults with dementia.

Data source: Local data collection, for example, a survey of people with dementia.

What the quality statement means for different audiences

Service providers (general practices, secondary care services, memory clinics, tertiary referral clinics, neurology clinics and geriatric medicine clinics) ensure that systems are in place to investigate reversible causes of cognitive decline. Specialist dementia diagnostic services and referral pathways should be in place so that adults with suspected dementia can be referred after reversible causes have been investigated.

Healthcare professionals (such as GPs, psychologists, neurologists and geriatricians) investigate reversible causes of cognitive decline, such as delirium, depression, sensory impairment (such as sight or hearing loss) or cognitive impairment from medicines associated with increased anticholinergic burden. If dementia is still suspected, they discuss referral with the person with suspected dementia, and refer them to a specialist dementia diagnostic service if the person agrees to this.

Commissioners (clinical commissioning groups and NHS England) ensure that they commission services that have agreed referral pathways to a specialist dementia diagnostic service for adults with suspected dementia and no reversible causes of cognitive decline.

Adults with symptoms of dementia have checks to see if something else is causing their symptoms. If dementia is still suspected, they have a discussion with the doctor about referral and, if they agree to it, they are referred to a specialist service for tests to find out whether they have dementia and, if so, what type they have.

Source guidance

[Dementia: assessment, management and support for people living with dementia and their carers](#) (2018) NICE guideline NG97, recommendation 1.2.6

Definitions of terms used in this quality statement

Suspected dementia

Dementia that is suspected after reversible causes of cognitive decline (including delirium, depression, sensory impairment [such as sight or hearing loss] or cognitive impairment from medicines associated with increased anticholinergic burden) have been investigated. [NICE's guideline on [dementia](#), recommendation 1.2.6]

Referred to a specialist dementia diagnostic service

A specialist dementia diagnostic service might be a memory clinic or community old age psychiatry service. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to support and treatment after diagnosis. Specialists are those with the appropriate knowledge and skills and include secondary care medical specialists (for example psychiatrists, geriatricians and neurologists) and other healthcare professionals (for example GPs, nurse consultants and advanced nurse practitioners) with specialist expertise in assessing and diagnosing dementia. [NICE's guideline on [dementia](#), recommendation 1.2.6 and terms used in this guideline]

Equality and diversity considerations

Recommendation 1.1.2 in the NICE guideline on [dementia](#) highlights that if needed, additional or modified ways of communicating (for example visual aids or simplified text) should be used.

Quality statement 3: Named care coordinator

Quality statement

Adults with dementia have a named care coordinator. [2010, updated 2019]

Rationale

Dementia is a progressive condition with symptoms and need for care and support changing over time. People with dementia often have other long-term conditions, such as cardiovascular disease and diabetes. Many different practitioners might be involved in supporting the health and social care needs of people with dementia. A single named practitioner who is familiar with the person with dementia is likely to notice issues as they arise and so prevent crises. They can also help to prevent missed and duplicate appointments, to make arrangements to cover changes in staffing, to support the person with communication if needed, and to provide a familiar face. The person with dementia can develop and review a care and support plan with their named practitioner. This will enable person-centred care.

Quality measures

Structure

a) Evidence of local arrangements to ensure that adults with dementia have a single named health or social care practitioner to coordinate their care.

Data source: Local data collection, for example, service specifications.

b) Evidence of local agreement of the role and functions of the named care coordinator.

Data source: Local data collection, for example, service specifications and job descriptions.

Process

a) Proportion of adults with dementia who have a named health or social care practitioner responsible for coordinating their care.

Numerator – the number in the denominator who have a named health or social care practitioner responsible for coordinating their care.

Denominator – the number of adults with dementia.

Data source: Local data collection. An indicator was piloted and shown to be feasible by the NICE indicator programme. See NICE indicator [NM64](#).

b) Proportion of adults with dementia who have a care and support plan.

Numerator – the number in the denominator who have a care and support plan.

Denominator – the number of adults with dementia.

Data source: Local data collection, for example, local audit of patient records.

Outcomes

a) Self-reported or carer-reported quality of life of adults with dementia.

Data source: Local data collection, for example, a survey of people with dementia.

b) Carer-reported quality of life of carers of adults with dementia.

Data source: Local data collection, for example, a survey of carers of people with dementia.

What the quality statement means for different audiences

Service providers (such as dementia adviser services, local authorities, general practices, memory clinics and community care providers) ensure that systems are in place to identify and assign a single named health or social care professional to coordinate care for a person with dementia.

Health or social care practitioners (such as GPs, community psychiatric nurses, community matrons, psychologists, dementia advisers, occupational therapists or social workers) who are responsible for coordinating health and social care for a person with dementia get to know the person and their needs and preferences, and develop and review a care and support plan to ensure that services and care are delivered in a coordinated and timely manner.

Commissioners (such as local authorities, clinical commissioning groups and NHS England) ensure that they commission services in which people with dementia are assigned a single named health or social care professional to coordinate their care. Commissioners make sure there is local agreement on the role and responsibilities of the care coordinator.

Adults with dementia are told who in their care team has been chosen to coordinate their care and be their contact, and are given clear and up-to-date contact details for that person. The contact should keep the person and their family at the centre of all decisions.

Source guidance

[Dementia: assessment, management and support for people living with dementia and their carers](#) (2018) NICE guideline NG97, recommendation 1.3.1

Definitions of terms used in this quality statement

Named care coordinator

A single named health or social care practitioner who is responsible for coordinating care. The named practitioner should:

- arrange an initial assessment of the person's needs, which should be face to face if possible
- provide information about available services and how to access them
- involve the person's family members or carers (as appropriate) in support and decision-making
- give special consideration to the views of people who do not have capacity to make decisions about their care, in line with the principles of the [Mental Capacity Act 2005](#)
- ensure that people are aware of their rights to and the availability of local advocacy services, and if appropriate to the immediate situation an independent mental capacity advocate
- develop a care and support plan, and:

- agree and review it with the involvement of the person, their family members or carers (as appropriate) and relevant professionals
- specify in the plan when and how often it will be reviewed
- evaluate and record progress towards the objectives at each review
- ensure it covers the management of any comorbidities
- provide a copy of the plan to the person and their family members or carers (as appropriate).

[NICE's guideline on [dementia](#), recommendations 1.3.1 and 1.3.2]

Equality and diversity considerations

Barriers to communication can hinder people's understanding of how they can be involved in their care. These barriers could include: mental health problems, learning or cognitive difficulties; physical, sight, speech or hearing difficulties; or difficulties with reading, understanding or speaking English. Adjustments should be made to ensure that all people with dementia can work with their named care coordinator to plan their care, with access to an advocate if needed.

Recommendation 1.1.2 in the NICE guideline on [dementia](#) highlights that if needed, additional or modified ways of communicating (for example visual aids or simplified text) should be used.

Quality statement 4: Activities to promote wellbeing

Quality statement

Adults with dementia are given a choice of activities to promote wellbeing that are tailored to their preferences. **[2013, updated 2019]**

Rationale

The symptoms of dementia make it harder for a person to take part in activities, to engage socially, to maintain their independence, to communicate effectively, to feel in control and to care for themselves. Providing enjoyable and health-enhancing activities that are suitable for the stage of dementia can help with this. Understanding the activities that a person thinks are suitable and helpful, and adapting them to their strengths and needs, will make a person more likely to engage with the activities offered.

Quality measures

Structure

a) Evidence of local arrangements to ensure that a range of activities are available that promote wellbeing for adults with dementia.

Data source: Local data collection, for example, service specifications.

b) Evidence of local arrangements to ensure that professionals offering activities to promote wellbeing to adults with dementia discuss the person's preferences with them and tailor the activities to these.

Data source: Local data collection, for example, service protocols.

Process

a) Proportion of adults with dementia having a review of their care plan who have a discussion about activities to promote wellbeing.

Numerator – the number in the denominator who have a discussion about activities to promote wellbeing.

Denominator – the number of adults with dementia having a review of their care plan.

Data source: Local data collection, for example, local audit of care plans.

b) Proportion of adults with dementia who take part in a range of activities to promote wellbeing that are tailored to their preferences.

Numerator – the number in the denominator who take part in a range of activities to promote wellbeing that are tailored to their preferences.

Denominator – the number of adults with dementia.

Data source: Local data collection, for example, local audit of patient records.

Outcomes

a) Self-reported or carer-reported level of satisfaction with activities to promote wellbeing.

Data source: Local data collection, for example, patient surveys.

b) Self-reported or carer-reported quality of life of adults with dementia.

Data source: Local data collection, for example, a survey of people with dementia.

c) Level of independence of adults with dementia.

Data source: Local data collection, for example, a survey of people with dementia.

What the quality statement means for different audiences

Service providers (such as local authorities, community care providers, dementia adviser services and memory clinics) ensure that systems are in place for people with dementia to have a discussion about their preferences and needs, and to choose activities to promote wellbeing that are tailored to these.

Health and social care practitioners (such as occupational therapists, community psychiatric nurses, psychologists, care home nurses, healthcare assistants, activities coordinators, dementia advisers, wellbeing advisers and social workers) have a discussion with the person with dementia about life experiences, circumstances,

preferences, interests, strengths and needs. Based on this discussion, they help the person with dementia to choose activities to promote wellbeing that suit their preferences and needs.

Commissioners (such as local authorities and clinical commissioning groups) ensure that activities to promote wellbeing are available for people with dementia, and specify that providers offer adults with dementia these activities based on a discussion of their preferences and needs.

Adults with dementia talk about their life experiences, circumstances, preferences, interests, strengths and needs with a professional. They are then told about suitable activities that they can do to improve their wellbeing, such as joining a choir or a local walking group.

Source guidance

[Dementia: assessment, management and support for people living with dementia and their carers](#) (2018) NICE guideline NG97, recommendation 1.4.1

Definitions of terms used in this quality statement

Activities to promote wellbeing

Activities such as exercise, aromatherapy, art, gardening, baking, reminiscence therapy, music therapy, mindfulness and animal assisted therapy. [NICE's guideline on [dementia](#), full guideline and expert opinion]

Tailored to their preferences

Interventions that the person with dementia considers to be feasible, acceptable, suitable and helpful. The activities offered should be based on an understanding of that individual's unique set of life experiences, circumstances, preferences, strengths and needs. [NICE's guideline on [dementia](#), full guideline]

Equality and diversity considerations

Offers of activities need to take into account any mental health conditions and learning or physical disabilities that the person may have. Any information provided should be accessible to people with additional needs, such as physical, sensory or

learning disabilities. Recommendation 1.1.2 in the NICE guideline on [dementia](#) highlights that if needed, additional or modified ways of communicating (for example visual aids or simplified text) should be used.

Quality statement 5: Managing distress

Quality statement

Adults with dementia have a structured assessment before starting non-pharmacological or pharmacological treatment for distress. [2010, updated 2019]

Rationale

Dementia can lead to behaviours such as increased aggression, anxiety, apathy, agitation, depression, delusions, hallucinations and sleep disturbances. But these behaviours may have other causes such as pain, delirium or inappropriate care. They can have an impact on both the person with dementia and their carer. Understanding the causes of these behaviours and addressing them can prevent escalation of the situation and the use of unnecessary interventions, such as antipsychotic medication, which may not manage the symptoms effectively.

Quality measures

Structure

Evidence of local arrangements to ensure that adults with dementia have a structured assessment before starting non-pharmacological or pharmacological treatment for distress.

Data source: Local data collection, for example, from local protocols.

Process

Proportion of adults with dementia who have started non-pharmacological or pharmacological treatment for distress who had a structured assessment before starting treatment.

Numerator – the number in the denominator who had a structured assessment before starting non-pharmacological or pharmacological treatment for distress.

Denominator – the number of adults with dementia who have started non-pharmacological or pharmacological treatment for distress.

Data source: Local data collection, for example, local audit of patient records.

Outcomes

a) Antipsychotic prescribing rates for adults with dementia.

Data source: NHS Digital publishes data on prescribing of antipsychotic medication in its [recorded dementia diagnoses](#) data collection.

b) Self-reported or carer-reported quality of life of adults with dementia.

Data source: Local data collection, for example, a survey of people with dementia.

What the quality statement means for different audiences

Service providers (such as community mental health services, secondary care services, general practices, local authorities and community care providers) ensure that arrangements are in place for professionals to carry out a structured assessment for adults with dementia to check for and address clinical or environmental causes of distress before starting treatment for distress.

Health and social care professionals (such as occupational therapists, community psychiatric nurses, psychiatrists, community matrons, clinical psychologists, neurologists, geriatricians, social workers and GPs) carry out a structured assessment for adults with dementia showing signs of distress, such as agitation or aggression, to explore the reasons for the distress before starting treatment. As part of the assessment, they check for any clinical or environmental causes of distress, for example pain, discomfort, delirium, inappropriate care, infection, boredom, noise or temperature, using appropriate assessment tools and involving other professionals if needed. When the cause of distress has been determined, they decide how to address this, and whether another professional or specialist service needs to be involved.

Commissioners (such as local authorities, clinical commissioning groups and NHS England) ensure that services have systems in place to carry out a structured assessment for adults with dementia to explore reasons for distress before starting treatment. The assessment should include checking for and addressing any clinical or environmental causes of distress, for example pain, delirium or inappropriate care.

Adults with dementia have checks to see if there are any reasons why they are distressed and if so what can be done. Reasons might include pain, infection, or not having the right care. Professionals address any of these issues before starting treatment for distress.

Source guidance

[Dementia: assessment, management and support for people living with dementia and their carers](#) (2018) NICE guideline NG97, recommendation 1.7.1

Definitions of terms used in this quality statement

Structured assessment

A multifactorial assessment to explore reasons for distress by checking for clinical causes, environmental impacts, medication issues, communication issues and sensory issues, using appropriate assessment tools. [Expert opinion and NICE's guideline on [dementia](#), recommendation 1.7.1]

Equality and diversity considerations

Recommendation 1.1.2 in the NICE guideline on [dementia](#) highlights that if needed, additional or modified ways of communicating (for example visual aids or simplified text) should be used.

Quality statement 6: Advance care planning

Quality statement

Adults with dementia have the opportunity to discuss advance care planning at diagnosis and at each health and social care review. **[2010, updated 2019]**

Rationale

As dementia is a progressive condition, it is important for people to be able to make decisions about their future care early on, before their communication deteriorates or they lack the capacity to do so. This is known as advance care planning. There needs to be opportunities to review and change the plan as dementia progresses and if the preferences or needs of the person living with dementia change. Having an advance care plan ensures that the person with dementia can be treated and cared for according to their preferences, even when they are unable to express them.

Quality measures

Structure

Evidence of local arrangements to ensure that adults with dementia and people involved in their care have early and ongoing opportunities to discuss advance care planning.

Data source: Local data collection, for example, from local protocols.

Process

a) Proportion of adults with dementia who have a documented discussion about advance care planning at diagnosis.

Numerator – the number in the denominator who have a documented discussion about advance care planning at diagnosis.

Denominator – the number of adults with a new diagnosis of dementia.

Data source: Local data collection, for example, local audit of patient records.

b) Proportion of adults with dementia having a health or social care review who have a documented discussion about advance care planning.

Numerator – the number in the denominator who have a documented discussion about advance care planning.

Denominator – the number of adults with dementia having a health or social care review.

Data source: Local data collection, for example, local audit of patient records.

Outcomes

a) Proportion of adults with dementia who feel encouraged to make decisions about their future care.

Data source: Local data collection, for example, a survey of people with dementia.

b) Proportion of adults with dementia who are aware they can update their advance care plan regularly.

Data source: Local data collection, for example, a survey of people with dementia.

What the quality statement means for different audiences

Service providers (such as memory clinics, community old age psychiatry services, local authorities, community care providers or general practices) ensure that systems are in place for adults with dementia and people involved in their care to have early and ongoing opportunities to discuss advance care planning.

Health and social care professionals (such as occupational therapists, psychiatrists, clinical psychologists, geriatricians, neurologists, GPs, nurse consultants, advanced nurse practitioners, social workers and palliative care teams) give adults with dementia and people involved in their care early and ongoing opportunities to discuss advance care planning.

Commissioners (such as local authorities, clinical commissioning groups and NHS England) ensure that they commission services that give adults with dementia and

people involved in their care early and ongoing opportunities to discuss advance care planning.

Adults with dementia and people involved in their care are supported to plan ahead and make decisions about future care, when dementia is diagnosed and whenever they have a care review.

Source guidance

[Dementia: assessment, management and support for people living with dementia and their carers](#) (2018) NICE guideline NG97, recommendation 1.1.12 and 1.1.13

Definitions of terms used in this quality statement

The opportunity to discuss advance care planning

An opportunity for discussion about:

- the benefits of planning ahead
- lasting power of attorney (for decisions about health, welfare, property and financial affairs)
- an advance statement about their wishes, preferences, beliefs and values regarding their future care
- advance decisions to refuse treatment
- their preferences for place of care and place of death
- any cultural or religious preferences or practices.

Opportunities should be given to review and change any advance statements and decisions made at each care review.

[Expert opinion and NICE's guideline on [dementia](#), recommendations 1.1.12 and 1.1.13]

Equality and diversity considerations

Adults with dementia, cognitive impairment, learning disabilities or language barriers may have difficulties communicating their preferences for care. Healthcare professionals caring for adults with dementia should establish the person's cognitive status, and if they have any speech, language or other communication needs; their

current level of understanding; and if they would like a person important to them to be present when discussing preferences about their care. All information provided should be accessible, as far as possible, to people with cognitive problems; and people receiving information should have access to an interpreter or advocate if needed.

Quality statement 7: Supporting carers

Quality statement

Carers of adults with dementia are offered education and skills training. [2010, updated 2019]

Rationale

Carers of adults with dementia often have high levels of stress due to the physical and mental challenges of caregiving, coping with other responsibilities, such as work or caring for children, health and mobility problems of their own, or financial issues. This affects their own physical and mental wellbeing. It is essential that carers have good support to enable them to manage the stresses and demands of caregiving and to fulfil their role. This includes both support for the specific challenges of caregiving and support to address their own needs.

Quality measures

Structure

a) Evidence that education and skills training are available for carers of adults with dementia.

Data source: Local data collection, for example, from service specifications or local protocols.

b) Evidence that education and skills training are tailored to the needs and preferences of carers of adults with dementia.

Data source: Local data collection, for example, from service specifications or local protocols.

Process

a) Proportion of carers of adults with dementia having a carers' assessment who have a discussion about education and skills training.

Numerator – the number in the denominator who have a discussion about education and skills training.

Denominator – the number of carers of adults with dementia having a carers' assessment.

Data source: Local data collection, for example, local audit of care plans for carers.

b) Proportion of carers of adults with dementia who take part in education and skills training.

Numerator – the number in the denominator who take part in education and skills training.

Denominator – the number of carers of adults with dementia.

Data source: Local data collection, for example, local audit of care plans for carers.

Outcomes

a) Carer-reported quality of life of carers of adults with dementia.

Data source: Local data collection, for example, a survey of carers of people with dementia. The Public Health England [Dementia Profile](#) includes data on carer-reported quality of life score for people caring for someone with dementia.

b) Carer-reported level of satisfaction with the tailoring of the support to their needs and preferences.

Data source: Local data collection, for example, a survey of carers of people with dementia.

c) Self-reported or carer-reported quality of life of adults with dementia.

Data source: Local data collection, for example, a survey of people with dementia.

What the quality statement means for different audiences

Service providers (such as general practices, local authorities, community care providers and secondary care services) provide training and support for carers of adults with dementia and tailor this to the needs and preferences identified in the carers' assessment.

Health and social care professionals (such as GPs, occupational therapists, community psychiatric nurses, psychiatrists, geriatricians, neurologists, clinical psychologists, practice nurses, hospital staff, Admiral nurses and social workers) tell carers of adults with dementia about training and support that is available that is suited to their needs and preferences.

Commissioners (such as local authorities, clinical commissioning groups and NHS England) ensure that training and support is available for carers of adults with dementia, and specify that this can be tailored to the needs and preferences identified in the carers' assessment.

Carers of adults with dementia are told how they can get training and support that is tailored to the needs and preferences identified in their carers' assessment.

Source guidance

[Dementia: assessment, management and support for people living with dementia and their carers](#) (2018) NICE guideline NG97, recommendation 1.11.1

Definitions of terms used in this quality statement

Education and skills training

Training and support that includes:

- education about dementia, its symptoms and the changes to expect as the condition progresses
- developing personalised strategies and building carer skills
- training to help them provide care, including how to understand and respond to changes in behaviour
- training to help them adapt their communication styles to improve interactions with the person living with dementia
- advice on how to look after their own physical and mental health, and their emotional and spiritual wellbeing
- advice on planning enjoyable and meaningful activities to do with the person they care for

- information about relevant services (including support services and psychological therapies for carers) and how to access them
- advice on planning for the future.

The support should be:

- tailored to their needs and preferences and to what they want it to achieve (for example, providing information on carer's employment rights for carers who work or want to work)
- designed to help them support people living with dementia
- available at a location they can get to easily
- provided in a format suitable for them (for example individual or group sessions, or online training and support)
- available from diagnosis and as needed after this.

[NICE's guideline on [dementia](#), recommendations 1.11.1 and 1.11.2]

Equality and diversity considerations

Offers of training and support for carers of adults with dementia need to take into account any physical or mental health conditions, and learning or physical disabilities that make it difficult to access training and support.

Update information

June 2019: This quality standard was updated and statements prioritised in 2010 and 2013 were replaced.

Statements are marked as:

- **[new 2019]** if the statement covers a new area for quality improvement
- **[2010 or 2013, updated 2019]** if the statement covers an area for quality improvement included in the 2010 or 2013 quality standard and has been updated.

Statements numbered 2, 4, 5, 6, and 7 in the 2010 version have been updated and are included in the updated quality standard, marked as **[2010, updated 2019]**. Statement 4 in the 2013 version has been updated and is included in the updated quality standard, marked as **[2013, updated 2019]**.

Statements from the 2010 version (numbered 1, 3, 8, 9 and 10) that are no longer considered national priorities for improvement, but may still be useful at a local level, are listed in the [quality statements](#) section. Statements from the 2013 version (numbered 1, 2, 3, 5, 6, 7, 8, 9 and 10) that are no longer considered national priorities for improvement, but may still be useful at a local level, are listed in the [quality statements](#) section.

The [2010 quality standard for Dementia: support in health and social care](#) and [2013 quality standard for Dementia: independence and wellbeing](#) are available as a pdf.

About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about [how NICE quality standards are developed](#) is available from the NICE website.

See [quality standard advisory committees](#) on the website for details of standing committee 3 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available on the [quality standard's webpage](#).

This quality standard has been included in the NICE Pathway on [dementia](#), which brings together everything we have said on a topic in an interactive flowchart.

NICE has produced a [quality standard service improvement template](#) to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references

to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Improving outcomes

This quality standard is expected to contribute to improvements in the following outcomes:

- dementia diagnosis rates
- time from referral to diagnosis
- hospital admission rates for people with dementia
- prescriptions for behavioural and psychological symptoms of dementia
- care home admissions
- length of hospital stay for people with dementia
- quality of life for people with dementia
- quality of life for carers of people with dementia.

It is also expected to support delivery of the Department of Health and Social Care outcome frameworks:

- [Adult social care outcomes framework](#)
- [NHS outcomes framework](#)
- [Public health outcomes framework for England](#).

Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. Organisations are encouraged to use the resource impact products for the source guidance to help estimate local costs:

- [costing report and template](#) for the NICE guideline on dementia: assessment, management and support for people living with dementia and their carers
- [costing statement](#) for the NICE guideline on dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset.

Diversity, equality and language

During the development of this quality standard, equality issues were considered and [equality assessments](#) are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

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