

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Draft quality standard – social care

Dementia – supporting people to live well with dementia

1 Introduction

In 2011, the National Institute for Health and Clinical Excellence (NICE) was asked by the Department of Health to pilot the development of 2 quality standards for social care. This builds on earlier work in 2009 to establish a quality standards programme for healthcare.

Dementia is a term that is used to describe a collection of symptoms including memory loss, problems with reasoning and communication skills, and a reduction in a person's abilities and skills in carrying out daily activities such as washing, dressing and cooking. The most common types of dementia are: Alzheimer's disease, vascular dementia, fronto-temporal dementia and dementia with Lewy bodies. It is a progressive condition, which means the symptoms will gradually get worse. This progression will vary from person to person and each will experience dementia in a different way – people may often have some of the same general symptoms, but the degree to which they affect an individual will vary ([Dementia Gateway](#), Social Care Institute for Excellence).

This draft quality standard is designed to improve quality of care by focusing on high-priority areas for people living with dementia. The standard is made up of a set of measurable statements, which together with the guidance on which it is based, should contribute to improving the overall experience of care or services in the following ways:

- Enhancing quality of life for people with care and support needs.
- Delaying and reducing the need for care and support.

- Ensuring that people have a positive experience of care and support.
- Safeguarding people whose circumstances make them vulnerable and protecting them from avoidable harm.

These overarching outcomes are from [The Adult Social Care Outcomes Framework 2011–12](#).

The quality standard is also expected to contribute to the following overarching outcome(s) from the [Public Health Outcomes Framework 2013–2016](#):

- Improving the wider determinants of health.
- Health improvement.
- Health protection.
- Healthcare public health and preventing premature mortality.

This quality standard was developed in line with a [scope](#) that outlines what the standard will and will not consider. During development the Topic Expert Group (TEG) appointed to develop this quality standard has decided which areas and activities described in the scope should be prioritised for the development of quality statements and measures. This draft quality standard covers how services can support people to live well with dementia.

This draft quality standard is being produced collaboratively with social care organisations and the NHS, along with their partners, people who use services and carers.

The quality standard development process for the 2 pilot topics is described in detail on the NICE website (see [NICE quality standards in social care](#)).

2 Draft quality standard for dementia – supporting people to live well with dementia

2.1 Overview

Quality standards, along with practical support tools, will help commissioners and service providers decide how best to provide and commission social care services, taking into account individual circumstances and professional judgement. They will also help people find information about the quality of services they should expect to receive and to hold commissioners to account. Quality standards support the role of [HealthWatch](#) (launching in October 2012) as a consumer champion. Social care communities will need to work with the NHS to ensure that they provide a comprehensive service for all.

The [Health and Social Care Act \(2012\)](#) sets out a new responsibility for NICE to develop quality standards and other guidance for social care in England. The Secretary of State for Health will formally commission NICE to develop additional quality standards for social care, taking advice from a consultative body on the choice and prioritisation of topics. The care and support white paper [Caring for our future: reforming care and support](#) (2012) sets out further detail on the future role of NICE quality standards in the social care sector, including the use of NICE quality standards as part of a new provider quality profile. Quality standards for social care will link with corresponding topics published for the NHS. They will be developed in full consultation with the social care and other relevant sectors, and will be presented and disseminated in ways that meet the needs of the social care community. As we develop this library of quality standards, we will cross refer to any published NICE quality standards for the NHS that make reference to social care, and consider these links during the quality standards update process.

A person-centred and integrated approach to the provision of care and support services is fundamental to the delivery of high quality care to people living with dementia. Different agencies will need to work closely together to achieve the level of care set out in the draft quality standard. This requires

that services should be commissioned from and coordinated across all relevant involved agencies.

2.2 List of quality statements

No.	Draft quality statements
1	People who are concerned that they or someone they know may have dementia are listened to and have opportunities to discuss such concerns.
2	People who might have dementia are informed of the benefits of attending a memory assessment service and encouraged to do so.
3	People living with dementia and their carers are in contact with a local adviser who provides information about dementia and how to access additional support.
4	People living with dementia and their carers have choice and control in decisions affecting their care and support.
5	People living with dementia have a care and support plan based on individual needs.
6	People living with dementia and their carers take part in a review of their care and support needs when their circumstances change and at least once a year.
7	People in the early stages of dementia and their carers have opportunities to be involved in planning their palliative and end-of-life care.
8	People living with dementia are supported to participate in activities based on individual interest and choice.
9	People living with dementia are supported to maintain relationships and have opportunities to contribute to the wider community.
10	People living with dementia are supported to access services that help maintain their physical and mental wellbeing.
11	People living with dementia have their accommodation designed or adapted to meet their specific needs.
12	People living with dementia and their carers have opportunities to be involved in planning and evaluating services.
13	People living with dementia and their carers are supported to access independent advocacy services.

In addition, quality standards that should also be considered when commissioning and providing a high-quality service are listed in section 7.

General questions for consultation	
Question 1	How will this quality standard improve the quality of care provided?
Question 2	What important areas of care or services, if any, are not covered by this quality standard?
Question 3	How useful are each of the proposed quality statements?
Question 4	Which are the most important quality statements and why?
Question 5	Are any of the proposed quality statement inappropriate and if so why?
Question 6	How measurable are each of the proposed quality statements - how easy will it be to collect data for each statement?
Question 7	Are any of the proposed quality measures inappropriate and, if so why, and can you identify suitable alternatives?
Question 8	Are there any additional quality measures that should be included?
Question 9	Can you suggest how we should show alignment between this quality standard and the published quality standard for dementia (appendix 2)
Please refer to Quality standards in development for additional general points for consideration.	

Draft quality statement 1: Concerns about possible dementia

Draft quality statement	People who are concerned that they or someone they know may have dementia are listened to and have opportunities to discuss such concerns.
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure people who are concerned that they or someone they know may have dementia are listened to and have opportunities to discuss such concerns.</p> <p>Outcome: Feedback that people concerned that they or someone they know may have dementia were listened to and given opportunities to discuss such concerns.</p>
Description of what the quality statement means for each audience	<p>People who are concerned that they or someone they know may have dementia are listened to and have opportunities to discuss their concerns.</p> <p>Local authorities and others commissioning services ensure the services they commission demonstrate how staff listen to people who are concerned that they or people they know may have dementia and give them the opportunity to discuss their concerns.</p> <p>Organisations providing care and support ensure they provide information resources to raise awareness and encourage discussion of concerns about possible dementia.</p> <p>Social care and healthcare staff ensure they listen to people who are concerned that they or someone they know may have dementia and provide them with opportunities to discuss their concerns.</p>
Source guidance	SCIE guide 15 : communication.
Data source	<p>Structure: Local data collection.</p> <p>Outcome: Local data collection.</p>
Equality and diversity considerations	Social care and healthcare staff should be aware of the special needs of younger people with dementia and people with learning disabilities (NICE clinical guideline 42 recommendation 1.1.2.1, 1.1.3.1 and 1.1.3.1).

Draft quality statement 2: Encouraging attendance at memory assessment services

Draft quality statement	People who might have dementia are informed of the benefits of attending a memory assessment service and encouraged to do so.
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure social care and healthcare staff are aware of the benefits of memory assessment services and how they can be accessed.</p> <p>Outcome: Feedback that people who might have dementia were informed of the benefits of attending a memory assessment service and received encouragement to do so.</p>
Description of what the quality statement means for each audience	<p>People who might have dementia are told about the benefits of a memory assessment service and are encouraged to attend.</p> <p>Local authorities and others commissioning services ensure referral routes to memory assessment services are disseminated across health and social care.</p> <p>Organisations providing care and support ensure staff have access to information on local memory assessment services.</p> <p>Social care and healthcare staff ensure they inform people who might have dementia of the benefits of memory assessment services and encourage them to attend.</p>
Source guidance	NICE clinical guideline 42 recommendation 1.3.3.1.
Data source	<p>Structure: Local data collection.</p> <p>Outcome: Local data collection.</p>
Equality and diversity considerations	NICE clinical guideline 42 recommendation 1.1.1.1, highlights that people should not be excluded from services because of diagnosis, age or coexisting learning disabilities.

Draft quality statement 3: Local advice

Draft quality statement	People living with dementia and their carers are in contact with a local adviser who provides information about dementia and how to access additional support.
Draft quality measure	<p>Structure: Evidence of local arrangements to provide a local adviser who provides information about dementia and how to access additional support.</p> <p>Process:</p> <p>a) Proportion of people living with dementia who are contacted by a local adviser who provides information about dementia and how to access additional support.</p> <p>Numerator – the number of people in the denominator contacted by a local adviser who provides information about dementia and how to access additional support.</p> <p>Denominator – the number of people with dementia.</p> <p>b) Proportion of carers of people living with dementia who are contacted by a local adviser who provides information about dementia and how to access additional support.</p> <p>Numerator – the number of carers in the denominator contacted by a local adviser who provides information about dementia and how to access additional support.</p> <p>Denominator – the number of carers of people living with dementia.</p> <p>Outcome: Feedback that people living with dementia and their carers are in contact with a local adviser who provides information about dementia and how to access additional support.</p>
Description of what the quality statement means for each audience	<p>People living with dementia and their carers are in contact with a local adviser who provides information about dementia and details of how to get extra support.</p> <p>Local authorities and others commissioning services ensure there are local advisers who provide information about dementia and how to access additional support.</p> <p>Organisations providing care and support ensure staff have access to the contact details of a local adviser who provides information about dementia and how to access additional support.</p> <p>Social care and healthcare staff ensure they know how to contact a local adviser who provides information about dementia and how to access additional support.</p>
Source guidance	NICE clinical guideline 42 recommendation 1.2.1.3

Data source	<p>Structure: Local data collection.</p> <p>Process: Local data collection.</p> <p>Outcome: Local data collection.</p>
Definitions	<p>Carers</p> <p>The Department of Health defines a carer as someone who provides unpaid support to family or friends who couldn't manage without this help, whether they're caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.</p> <p>Local adviser</p> <p>This role could be performed by a 'dementia adviser', a role that is being piloted as a result of the National Dementia Strategy.</p>
Equality and diversity considerations	<p>NICE clinical guideline 42 recommendation 1.1.1.7, lists alternative and additional support that may be needed if language or acquired language impairment is a barrier to accessing or understanding support.</p> <p>Social care and healthcare staff should be aware of the special needs of younger people with dementia and people with learning disabilities (NICE clinical guideline 42 recommendation 1.1.2.1, 1.1.3.1 and 1.1.3.1).</p>

Draft quality statement 4: Choice and control in decision-making

Draft quality statement	People living with dementia and their carers have choice and control in decisions affecting their care and support.
Draft quality measure	<p>Structure:</p> <p>a) Evidence of local arrangements to ensure that people living with dementia and their carers understand their options for care and support.</p> <p>b) Evidence that staff are trained in recognising and responding to the voice of people with dementia.</p> <p>c) Evidence of local arrangements to ensure that people living with dementia who are eligible are offered personal budgets.</p> <p>Process: Proportion of people living with dementia who use a personal budget.</p> <p>Numerator – the number of people in the denominator using a personal budget.</p> <p>Denominator – the number of people living with dementia who are eligible for a personal budget.</p> <p>Outcome:</p> <p>a) Feedback that people living with dementia and their carers understand their options for care and support.</p> <p>b) Feedback that people living with dementia and their carers feel their voice is heard and that they have choice and control in decisions affecting their care and support.</p>
Description of what the quality statement means for each audience	<p>People living with dementia and their carers have choice and control in decisions affecting their care and support.</p> <p>Local authorities and others commissioning services ensure they assess how services support people with dementia to exercise choice and control in decisions affecting their care and support and monitor the use of personal budgets for people living with dementia.</p> <p>Organisations providing care and support ensure they can demonstrate how people living with dementia and their carers have choice and control in decisions affecting their care and support.</p> <p>Social care and healthcare staff ensure people living with dementia and their carers are supported in making decisions about their care and support.</p>
Source guidance	<p>NICE clinical guideline 42 recommendations 1.1.1.5 and 1.1.8.1</p> <p>SCIE guide 15: choice and control</p>

Data source	<p>Structure: Local data collection.</p> <p>Process: National indicator 130 (VSC17) – social care clients receiving self-directed support (direct payments and individual budgets).</p> <p>Outcome: Local data collection.</p>
Equality and diversity considerations	<p>NICE clinical guideline 42 recommendation 1.1.1.7, lists alternative and additional support that may be needed if language or acquired language impairment is a barrier to accessing or understanding support.</p> <p>The Mental Capacity Act Code of Practice provides guidance to anyone who is working with or caring for adults who may lack capacity to make particular decisions.</p>

Draft quality statement 5: Care and support plans

Draft quality statement	People living with dementia have a care and support plan based on individual needs.
Draft quality measure	<p>Structure:</p> <p>a) Evidence of local arrangements to ensure people with dementia have care and support plans based on their individual needs.</p> <p>b) Evidence of local arrangements to ensure that people living with dementia who are eligible are offered personal budgets.</p> <p>Process: Proportion of people living with dementia who have a care and support plan based on their individual needs.</p> <p>Numerator – the number of people in the denominator who have a care and support plan based on their individual needs.</p> <p>Denominator – the number of people living with dementia.</p> <p>Outcome: Feedback that people living with dementia feel their care and support is suited to their needs.</p>
Description of what the quality statement means for each audience	<p>People living with dementia have a care and support plan that meets their individual needs.</p> <p>Local authorities and others commissioning services ensure they assess whether care and support plans are based on individual needs.</p> <p>Organisations providing care and support ensure care and support plans for people living with dementia are based on individual needs.</p> <p>Social care staff ensure care and support plans for people living with dementia are based on individual needs.</p>
Source guidance	<p>NICE clinical guideline 42 recommendations 1.1.1.3, 1.1.1.4, 1.1.1.5, 1.1.7.2 and 1.5.1.1</p> <p>SCIE guide 15: choice and control</p> <p>SCIE guide 15: practical assistance</p> <p>SCIE guide 47: what is personalisation?</p>
Data source	<p>Structure: Local data collection.</p> <p>Process: Local data collection.</p> <p>Outcome: Local data collection.</p>

<p>Equality and diversity considerations</p>	<p>NICE clinical guideline 42 recommendations 1.1.1.3 to 1.1.1.5, list the types of specific needs and preferences that care and support plans should record and address.</p> <p>Social care and healthcare staff should be aware of the special needs of younger people with dementia and people with learning disabilities (NICE clinical guideline 42 recommendation 1.1.2.1, 1.1.3.1 and 1.1.3.1).</p> <p>NICE clinical guideline 42 recommendation 1.1.1.7, lists alternative and additional support that may be needed if language or acquired language impairment is a barrier to accessing or understanding support.</p> <p>The Mental Capacity Act Code of Practice provides guidance to anyone who is working with or caring for adults who may lack capacity to make particular decisions.</p>
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Draft quality statement 6: Reviewing needs

Draft quality statement	People living with dementia and their carers take part in a review of their care and support needs when their circumstances change and at least once a year.
Draft quality measure	<p>Structure:</p> <p>a) Evidence of local arrangements to ensure that changes in the circumstances of people living with dementia or their carers trigger a review of their care and support needs.</p> <p>b) Evidence of local arrangements to ensure that people living with dementia and their carers take part in a review of their care and support needs at least once a year.</p> <p>Process:</p> <p>a) Proportion of people living with dementia who have had their care and support needs reviewed in the past 12 months. Numerator – the number of people in the denominator who have had their care and support needs reviewed in the past 12 months. Denominator – the number of people living with dementia.</p> <p>b) Proportion of carers of people living with dementia who have had their care and support needs reviewed in the past 12 months. Numerator – the number of people in the denominator who have had their care and support needs reviewed in the past 12 months. Denominator – the number of carers of people living with dementia.</p> <p>Outcome: Feedback from people living with dementia and their carers that they have reviews of their care and support needs when their circumstances change and at least once a year.</p>
Description of what the quality statement means for each audience	<p>People living with dementia and their carers take part in a review of their care and support needs when their circumstances change and at least once a year.</p> <p>Local authorities and others commissioning services ensure they monitor whether the care and support needs of people living with dementia and their carers are reviewed when their circumstances change and at least once a year.</p> <p>Organisations providing care and support ensure the care and support needs of people living with dementia and their carers are reviewed at least once a year.</p> <p>Social care staff ensure the care and support needs of people living with dementia and their carers are reviewed in response to changes in circumstances.</p>
Source guidance	NICE clinical guideline 42 recommendations 1.1.7.3, 1.5.1.1, 1.7.3.1 and 1.10.2.1
Data source	Structure: Local data collection.

	<p>Process: a) Local data collection.</p> <p>b) National indicator 135 (VSC18) – carers receiving needs assessment or review and a specific carer’s service advice or information.</p> <p>Outcome: Local data collection.</p>
Definitions	<p>Carers</p> <p>The Department of Health defines a carer as someone who provides unpaid support to family or friends who couldn’t manage without this help, whether they’re caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.</p> <p>Changes in circumstances</p> <p>‘Changes in their circumstances’ refers equally to changes experienced by people with dementia and changes experienced by their carers. This includes changes in:</p> <ul style="list-style-type: none"> • care and support needs • behaviour • preferences • personal circumstances • the condition of the person with dementia.
Equality and diversity considerations	<p>The Mental Capacity Act Code of Practice provides guidance to anyone who is working with or caring for adults who may lack capacity to make particular decisions.</p>

Draft quality statement 7: Palliative and end-of-life care

Draft quality statement	People in the early stages of dementia and their carers have opportunities to be involved in planning their palliative and end-of-life care.
Draft quality measure	<p>Structure: Evidence of local arrangements to provide opportunities for people in the early stages of dementia and their carers to be involved in planning their palliative and end-of-life care</p> <p>Process:</p> <p>a) Proportion of people offered an opportunity in the early stages of dementia to be involved in planning their palliative and end-of-life care.</p> <p>Numerator – the number of people in the denominator offered an opportunity in the early stages of dementia to be involved in planning their palliative and end-of-life care.</p> <p>Denominator – the number of people living with dementia.</p> <p>b) Proportion of carers of people living with dementia who were offered an opportunity in the early stages of dementia to be involved in planning palliative and end-of-life care.</p> <p>Numerator – the number of carers in the denominator offered an opportunity in the early stages of dementia to be involved in planning palliative and end-of-life care.</p> <p>Denominator – the number of carers of people living with dementia</p> <p>c) Proportion of people involved in planning their palliative and end-of-life care in the early stages of dementia.</p> <p>Numerator – the number of people in the denominator involved in planning their palliative and end-of-life care in the early stages of dementia.</p> <p>Denominator – the number of people living with dementia.</p> <p>d) Proportion of carers of people living with dementia who were involved in planning palliative and end-of-life care in the early stages.</p> <p>Numerator – the number of carers in the denominator involved in planning palliative and end-of-life care in the early stages of dementia.</p> <p>Denominator – the number of carers of people living with dementia.</p> <p>Outcome: Feedback that carers of people with dementia in the last days of life feel everything was done to meet the person’s needs and preferences.</p>

<p>Description of what the quality statement means for each audience</p>	<p>People in the early stages of dementia and their carers have opportunities to be involved in planning their palliative and end-of-life care.</p> <p>Local authorities and others commissioning services ensure they assess how services provide opportunities for people in the early stages of dementia and their carers to be involved in planning their palliative and end-of-life care.</p> <p>Organisations providing care and support ensure that planning for palliative and end-of-life care is undertaken in the early stages of dementia.</p> <p>Social and healthcare staff ensure that people in the early stages of dementia and their carers have opportunities to be involved in planning their palliative and end-of-life care.</p>
<p>Source guidance</p>	<p>NICE clinical guideline 42 recommendations 1.10.1.1 and 1.10.1.2.</p> <p>SCIE guide 15: specialist care.</p>
<p>Data source</p>	<p>Structure: Local data collection.</p> <p>Process: Local data collection.</p> <p>Outcome: Local data collection.</p>
<p>Definitions</p>	<p>Carers</p> <p>The Department of Health defines a carer as someone who provides unpaid support to family or friends who couldn't manage without this help, whether they're caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.</p> <p>Early stages of dementia</p> <p>'Early stages' refers to when the person with dementia still has capacity to understand and express their choices about palliative and end-of-life care.</p>
<p>Equality and diversity considerations</p>	<p>NICE clinical guideline 42 recommendation 1.1.1.1, highlights that people should not be excluded from services because of diagnosis, age or coexisting learning disabilities.</p> <p>The Mental Capacity Act Code of Practice provides guidance to anyone who is working with or caring for adults who may lack capacity to make particular decisions.</p>

Draft quality statement 8: Supporting participation in activities

Draft quality statement	People living with dementia are supported to participate in activities based on individual interest and choice.
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure that people living with dementia have access to and are supported to participate in activities based on individual interest and choice.</p> <p>Outcome: Feedback that people living with dementia feel supported to participate in activities based on their interest and personal choice.</p>
Description of what the quality statement means for each audience	<p>People living with dementia are supported to take part in activities that interest them and that they choose.</p> <p>Local authorities and others commissioning services ensure they assess how the services they commission support people living with dementia to participate in activities of interest.</p> <p>Organisations providing care and support ensure they provide a range of activities of interest for people living with dementia .</p> <p>Social care and healthcare staff ensure they respect the choices of people living with dementia and provide support to participate in activities of interest.</p>
Source guidance	<p>NICE clinical guideline 42 recommendations 1.1.7.2 and 1.5.1.1</p> <p>SCIE guide 15: choice and control</p>
Data source	<p>Structure: Local data collection.</p> <p>Outcome: Local data collection.</p>
Equality and diversity considerations	The Mental Capacity Act Code of Practice provides guidance to anyone who is working with or caring for adults who may lack capacity to make particular decisions.

Draft quality statement 9: Relationships and the wider community

Draft quality statement	People living with dementia are supported to maintain relationships and have opportunities to contribute to the wider community.
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure that people living with dementia can maintain relationships and contribute to the wider community.</p> <p>Outcome:</p> <p>a) Feedback that people living with dementia are supported to maintain relationships and have opportunities to contribute to the wider community.</p> <p>b) Feedback that people living with dementia are supported to maintain their independence and feel less stigmatised in the community.</p>
Description of what the quality statement means for each audience	<p>People living with dementia are supported to continue their relationships and take part in activities in their community.</p> <p>Local authorities and others commissioning services ensure they assess how the services they commission support people living with dementia to maintain relationships and contribute to the wider community.</p> <p>Organisations providing care and support ensure people living with dementia can maintain relationships and provide a range of opportunities to contribute to the wider community.</p> <p>Social care staff ensure they support people living with dementia to maintain relationships and access opportunities to contribute to the wider community.</p>
Source guidance	<p>NICE clinical guideline 42 recommendations 1.1.5.1, 1.1.7.2 and 1.5.1.1</p> <p>SCIE guide 15: social inclusion</p> <p>SCIE guide 15: choice and control</p>
Data source	<p>Structure: Local data collection.</p> <p>Outcome: Local data collection.</p>

Draft quality statement 10: Physical and mental wellbeing

Draft quality statement	People living with dementia are supported to access services that help maintain their physical and mental wellbeing.
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure systems are in place to support people living with dementia to access services that help maintain their physical and mental wellbeing.</p> <p>Outcome: Feedback that people living with dementia feel supported in maintaining their physical and mental wellbeing.</p>
Description of what the quality statement means for each audience	<p>People living with dementia are supported to access services that help maintain physical and mental wellbeing.</p> <p>Local authorities and others commissioning services ensure the services they commission to support people living with dementia are integrated with services that help maintain physical and mental wellbeing.</p> <p>Organisations providing care and support ensure information is available on how people living with dementia can access services that will help maintain their physical and mental wellbeing.</p> <p>Social care and healthcare staff ensure they support people living with dementia to access services that help maintain physical and mental wellbeing.</p>
Source guidance	<p>NICE clinical guideline 42 recommendations 1.1.1.4 and 1.8.1.1</p> <p>SCIE guide 15: pain management</p> <p>SCIE guide 15: eating and nutritional care</p>
Data source	<p>Structure: Local data collection.</p> <p>Outcome: Local data collection.</p>
Definitions	<p>Services that help maintain physical and mental wellbeing</p> <p>Examples of services helping to maintain physical and mental well-being include:</p> <ul style="list-style-type: none"> • occupational health services • primary healthcare teams • older people's mental health teams.
Equality and diversity considerations	<p>NICE clinical guideline 42 recommendation 1.1.1.1, highlights that people should not be excluded from services because of diagnosis, age or coexisting learning disabilities.</p>

Draft quality statement 11: Design and adaptation of accommodation

Draft quality statement	People living with dementia have their accommodation designed or adapted to meet their specific needs.
Draft quality measure	<p>Structure:</p> <p>a) Evidence of local arrangements to ensure that staff are trained to recognise when adaptations to accommodation can help meet the specific needs of people living with dementia.</p> <p>b) Evidence of local arrangements to ensure that accommodation is designed and adapted to meet the specific needs of people with dementia.</p> <p>Process:</p> <p>a) Proportion of people living with dementia and receiving care at home whose accommodation has been adapted to meet their specific needs.</p> <p>Numerator – the number of people in the denominator whose accommodation has been adapted to meet their specific needs.</p> <p>Denominator – the number of people living with dementia and receiving care at home.</p> <p>b) Proportion of care homes designed or adapted to meet the specific needs of people with dementia.</p> <p>Numerator – the number of care homes designed or adapted to meet the specific needs of people with dementia.</p> <p>Denominator – the number of care homes.</p> <p>Outcome: Feedback that people living with dementia feel alterations to where they live have helped them with their day-to-day life and to maintain their independence.</p>
Description of what the quality statement means for each audience	<p>People living with dementia have their accommodation designed or adapted to meet their specific needs.</p> <p>Local authorities and others commissioning services ensure they commission services that design or adapt accommodation to meet the specific needs of people living with dementia.</p> <p>Organisations providing care and support ensure accommodation is designed or adapted to meet the specific needs of people living with dementia.</p> <p>Social care and healthcare staff ensure they recognise when adaptations to accommodation can help meet the specific needs of people living with dementia.</p>
Source guidance	<p>NICE clinical guideline 42 recommendations 1.1.10.1, 1.1.10.2 and 1.1.10.3</p> <p>SCIE guide 15: practical assistance</p>

Data source	<p>Structure: Local data collection</p> <p>Process: Local data collection</p> <p>Outcome: Local data collection</p>
Definitions	<p>Specific components of accommodation include, but are not limited to:</p> <ul style="list-style-type: none"> • lighting • colour schemes • floor coverings • assistive technology • signage • outdoor space or gardens access

Draft quality statement 12: Planning and evaluating services

Draft quality statement	People living with dementia and their carers have opportunities to be involved in planning and evaluating services.
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure people living with dementia and their carers have opportunities to be involved in planning and evaluating services.</p> <p>Outcome: Feedback that people living with dementia and their carers take part in planning and evaluating services.</p>
Description of what the quality statement means for each audience	<p>People living with dementia and their carers are offered opportunities to take part in planning and evaluating services.</p> <p>Local authorities and others commissioning services ensure they assess how the services they commission offer opportunities for people living with dementia and their carers to be involved in planning and evaluating services.</p> <p>Organisations providing care and support ensure systems are in place to enable people living with dementia and their carers to be involved in planning and evaluating services.</p> <p>Social care and healthcare staff ensure they support people living with dementia and their carers to take up opportunities to be involved in planning and evaluating services.</p>
Source guidance	<p>NICE clinical guideline 42 recommendation 1.2.1.2.</p> <p>SCIE guide 15: choice and control.</p>
Data source	<p>Structure: Local data collection.</p> <p>Outcome: Local data collection.</p>
Definitions	<p>Carers</p> <p>The Department of Health defines a carer as someone who provides unpaid support to family or friends who couldn't manage without this help, whether they're caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.</p> <p>Involved</p> <p>In this statement, involvement refers to people being involved as participants, but also in the delivery of service evaluation and improvement; for example, contributing to the development of the evaluation criteria, being consulted on the evaluation design and any tools used to conduct the evaluation.</p>

Draft quality statement 13: Advocacy

Draft quality statement	People living with dementia and their carers are supported to access independent advocacy services.
Draft quality measure	<p>Structure:</p> <p>a) Evidence of local arrangements to ensure that people living with dementia and their carers can access independent advocacy services.</p> <p>b) Evidence of proactive approaches to reach people living with dementia and their carers who may have difficulty accessing advocacy.</p> <p>Process:</p> <p>a) Proportion of people living with dementia accessing independent advocacy services.</p> <p>Numerator – the number of people in the denominator accessing independent advocacy services.</p> <p>Denominator – the number of people living with dementia.</p> <p>b) Proportion of carers of people living with dementia accessing independent advocacy services.</p> <p>Numerator – the number of carers in the denominator accessing independent advocacy services.</p> <p>Denominator – the number of carers of people living with dementia.</p> <p>Outcome: Feedback that people living with dementia and their carers know how to contact independent advocacy services.</p>
Description of what the quality statement means for each audience	<p>People living with dementia, and their carers, are supported to access independent advocacy services.</p> <p>Local authorities and others commissioning services ensure they assess the availability of independent advocacy services for people living with dementia and their carers.</p> <p>Organisations providing care and support ensure people living with dementia and their carers are supported to access independent advocacy services.</p> <p>Social care and healthcare staff ensure they know how people living with dementia and their carers can access independent advocacy services.</p>
Source guidance	<p>SCIE guides 31, 32, 39 and 41.</p> <p>NICE clinical guideline 42 recommendation 1.1.4.2.</p> <p>SCIE guide 15: choice and control.</p>

Data source	<p>Structure: Local data collection.</p> <p>Process: Local data collection.</p> <p>Outcome: Local data collection.</p>
Definitions	<p>Carers</p> <p>The Department of Health defines a carer as someone who provides unpaid support to family or friends who couldn't manage without this help, whether they're caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.</p> <p>Advocacy</p> <p>Action for Advocacy state 'Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocates and advocacy schemes work in partnership with the people they support and take their side. Advocacy promotes social inclusion, equality and social justice'.</p> <p>Independent advocacy services can be provided by, but are not limited to:</p> <ul style="list-style-type: none"> • Independent Mental Capacity Advocates provided under the Mental Capacity Act 2005 • local user groups • charitable organisations.
Equality and diversity considerations	<p>NICE clinical guideline 42 recommendation 1.1.1.7, lists alternative and additional support that may be needed if language or acquired language impairment is a barrier to accessing or understanding support.</p> <p>The Mental Capacity Act Code of Practice provides guidance to anyone who is working with or caring for adults who may lack capacity to make particular decisions.</p>

3 Status of this quality standard

This is the draft quality standard released for consultation from 16 August to 16 October 2012. This document is not NICE's final quality standard on supporting people to live well with dementia. The statements and measures presented in this document are provisional and may change after consultation with stakeholders.

Comments on the content of the draft quality standard must be submitted by 5 pm on 16 October 2012. All eligible comments received during consultation will be reviewed by the Topic Expert Group and the quality statements and measures will be refined in line with the Topic Expert Group considerations. The final quality standard will then be available on the [NICE website](#) from April 2013.

4 Using the quality standard

It is important that the quality standard is considered alongside current policy and guidance documents listed in the development sources section (see appendix 1).

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care for people living with dementia. They are not a new set of targets or mandatory indicators for performance management.

Expected levels of achievement for quality measures are not specified. Because quality standards are intended to drive up the quality of care, achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, we recognise that this may not always be appropriate in practice when taking account of safety, choice and professional judgement and therefore desired levels of achievement should be defined locally.

We have shown where national indicators currently exist and measure the quality statement. National indicators may include those developed by the

Information Centre for Health and Social Care through their [Indicators for Quality Improvement Programme](#). For statements for which national quality indicators do not exist, the quality measures should form the basis for audit criteria developed and used locally to improve the quality of care. The Healthcare Quality Improvement Partnership is planning to pilot a new, nationally agreed, care audit for local use in 2013 and 2014, with a focus on dementia care in residential care settings to enable providers to improve the quality of care.

For further information, including guidance on using quality measures, please see [What makes up a NICE quality standard](#).

5 Diversity, equality and language

During the development of this quality standard, equality issues have been considered and equality assessments will be published on the NICE website with the final version of the quality standard.

Good communication between social care and healthcare services and people living with dementia is essential. Care and support, 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 living with dementia should have access to an interpreter or advocate if needed.

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

6 How this quality standard was developed

Quality standards are derived from the best available evidence, such as NICE guidance or other NICE accredited sources. The guidance used to underpin

this quality standard is listed in appendix 1, along with relevant policy context, definitions and data sources. Further explanation of the methodology used can be found in [Social care quality standards: interim process guide for pilot topics](#).

7 Related NICE quality standards

- [Patient experience in adult NHS services](#). NICE quality standard (2012).
- [End of life care for adults](#). NICE quality standard (2011).
- [Dementia](#). NICE quality standard (2010).

Appendix 1: Development sources

Evidence sources

The documents below contain recommendations that were used by the TEG to develop the quality standard.

Social Care Institute for Excellence (2011) [IMCA and paid relevant person's representative roles in the Mental Capacity Act Deprivation of Liberty Safeguards](#). SCIE guide 41.

Social Care Institute for Excellence (2010) [Personalisation: a rough guide](#). SCIE guide 47.

Social Care Institute for Excellence (2010) [Independent mental capacity advocate involvement in accommodation decisions and care reviews](#). SCIE guide 39.

Social Care Institute for Excellence (2010) [Dignity in care](#). SCIE guide 15.

Social Care Institute for Excellence (2009) [Practice guidance on the involvement of Independent Mental Capacity Advocates \(IMCAs\) in safeguarding adults](#). SCIE guide 32.

Social Care Institute for Excellence (2009) [Commissioning and monitoring of Independent Mental Capacity Advocate \(IMCA\) services](#). SCIE guide 31.

Social Care Institute for Excellence (2007) [Implementing the Carers \(Equal Opportunities\) Act 2004](#). SCIE guide 9.

NICE (2006) [Dementia: supporting people with dementia and their carers in health and social care](#). NICE clinical guideline 42.

Policy context

It is important that the quality standard is considered alongside current policy documents, including:

Department of Health (2012) [The dementia challenge](#)

Department of Health (2011) [NHS Outcomes Framework 2012–13](#)

Department of Health (2011) [Dementia commissioning pack](#)

Department of Health (2011) [National strategy for carers](#)

Department of Health (2011) [Transparency in outcomes: a framework for adult social care](#)

Department of Health (2011) [No health without mental health: a cross-government mental health outcomes strategy for people of all ages](#)

Department of Health, Skills for Health, Skills for Care (2011) [Common core principles for supporting people with dementia: a guide to training the social care and health workforce](#)

Department of Health (2010) [Nothing ventured, nothing gained: risk guidance for people with dementia](#)

Department of Health (2010) [Quality outcomes for people with dementia: building on the work of the National Dementia Strategy](#)

Department of Health (2010) [Dignity in care](#) (hosted by SCIE)

Department of Health (2010) [A vision for adult social care: capable communities and active citizens](#)

Department of Health (2009) [Joint commissioning framework for dementia](#)

Department of Health (2009) [The use of antipsychotic medication for people with dementia: time for action](#)

Department of Health (2009) [National dementia strategy](#)

Department of Health (2008) [Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own](#)

Ministry of Justice (2005) [Mental Capacity Act Code of Practice](#)

Definitions and data sources for the quality measures

References included in the definitions and data sources sections:

Data on Local Authority National Indicators available from the [National Adult Social Care Intelligence Service](#) (NASCIS)

Appendix 2: Quality standard for dementia

Below are the quality statements from the NICE [quality standard for dementia](#) (2010).

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 : <ul style="list-style-type: none"> • 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.