

Dementia: independence and wellbeing

Quality standard

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This standard is based on NG97.

This standard should be read in conjunction with QS1, QS13, QS15, QS50, QS63, QS123, QS136 and QS164.

Introduction and overview

Introduction

Dementia is a term used to describe a collection of symptoms including memory loss, problems with reasoning and communication, and a reduction in a person's ability to carry out daily activities such as washing, dressing and cooking. The most common types of dementia are: Alzheimer's disease, vascular dementia, mixed dementia and dementia with Lewy bodies. Dementia is a progressive condition, which means that 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 these affect each person will vary ([Dementia Gateway](#), Social Care Institute for Excellence).

This quality standard covers supporting people to live well with dementia. It applies to all social care settings and services working with and caring for people with dementia. It should be read alongside the NICE quality standard for [dementia: support in health and social care](#), which covers care provided by health and social care staff in direct contact with people with dementia in hospital, community, home-based, group care, residential or specialist care settings. The NICE Pathway on [dementia](#) presents the information from both quality standards in an integrated format.

In 2012, the [Prime Minister's challenge on dementia](#) recognised the low rates of formal diagnosis of dementia, and services were tasked with improvements. While this work is underway, the quality standard for supporting people to live well with dementia should not be regarded as applying solely to people with a formal diagnosis of dementia. The support it advocates should be available for all people with cognitive impairment that could be linked to probable dementia. For more information see the [scope](#).

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 guidance, which provide an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

The quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following frameworks:

- [The Adult Social Care Outcomes Framework 2013–14](#)
- [The NHS Outcomes Framework 2013–14](#)
- [Public Health Outcomes Framework for England 2013–16](#)

The table below shows the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving:

Adult Social Care Outcomes Framework 2013–14	
<p>Domain 1: Enhancing quality of life for people with care and support needs</p>	<p>Overarching measure</p> <p>1A. Social care related quality of life</p> <p>Outcome measures</p> <p><i>People manage their own support as much as they wish, so that they are in control of what, how and when support is delivered to match their needs.</i></p> <p>1B. Proportion of people who use services who have control over their daily life</p> <p><i>Carers can balance their caring roles and maintain their desired quality of life.</i></p> <p>1D. Carer-reported quality of life</p> <p><i>People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation.</i></p> <p>1I. Proportion of people who use services and their carers, who reported that they had as much social contact as they would like.</p>

<p>Domain 3: Ensuring people have a positive experience of care and support</p>	<p>Overarching measure</p> <p><i>People who use social care and their carers are satisfied with their experience of care and support services.</i></p> <p>3A. Overall satisfaction of people who use services with their care and support</p> <p>3B. Overall satisfaction of carers with social services</p> <p>3E: Improving people's experience of integrated care</p> <p>Outcome measures</p> <p><i>Carers feel that they are respected as equal partners throughout the care process.</i></p> <p>3C. The proportion of carers who report that they have been included or consulted in discussions about the person they care for</p> <p><i>People know what choices are available to them locally, what they are entitled to, and who to contact when they need help.</i></p> <p>3D. The proportion of people who use services and carers who find it easy to find information about support</p> <p><i>People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual.</i></p> <p>This information can be taken from the Adult Social Care Survey and used for analysis at the local level.</p>
<p>NHSOutcomesFramework2013-14</p>	

<p>Domain 2: Enhancing quality of life for people with long term conditions</p>	<p>Overarching indicator</p> <p>2 Health-related quality of life for people with long-term conditions</p> <p>Improvement area</p> <p><i>Ensuring people feel supported to manage their condition</i></p> <p>2.1 Proportion of people feeling supported to manage their condition</p> <p><i>Enhancing quality of life for carers</i></p> <p>2.4 Health-related quality of life for carers</p> <p><i>Enhancing quality of life for people with dementia</i></p> <p>2.6 i Estimated diagnosis rate for people with dementia</p> <p>2.6 ii A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life</p>
<p>Domain 4: Ensuring that people have a positive experience of care</p>	<p>Improvement area</p> <p><i>Improving people's experience of integrated care</i></p> <p>4.9 Indicator in development</p>
<p>Public Health Outcomes Framework 2013–16</p>	
<p>Domain 4: Healthcare public health and preventing premature mortality</p>	<p>Objective</p> <p>Reduced numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communities.</p> <p>4.16 Estimated diagnosis rate for people with dementia</p>

Overview

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 Act outlines a vision for establishing quality as the defining factor for health and social care, through the use of quality standards. The use of quality standards for health and social care can allow people to hold their local commissioners to account, can help guide the commissioning of efficient and effective services and can assist service providers and users to assess the quality of the services they are involved in.

Quality standards support the role of [HealthWatch](#) as a consumer champion. Social care providers will need to work with the NHS to ensure that they provide a comprehensive service for all.

From April 2013, NICE will develop a library of quality standards and guidance to improve the quality of social care, as part of an integrated approach with healthcare quality standards.

A person-centred and integrated approach to providing care and services is fundamental to delivering high-quality care for people with dementia.

The quality standard should be read in the context of national and local guidelines on training and competencies. All professionals involved in caring for and supporting people with dementia should be sufficiently and appropriately trained and competent to deliver the actions and interventions described in the quality standard.

The quality standard acknowledges the vital importance of involving carers of people with dementia. Services should consider how to ensure carers are involved in the implementation of each quality statement.

List of quality statements

Statement 1 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.

Statement 2 People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.

Statement 3 People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change.

Statement 4 People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.

Statement 5 People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.

Statement 6 People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

Statement 7 People with dementia live in housing that meets their specific needs.

Statement 8 People with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.

Statement 9 People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.

Statement 10 People with dementia are enabled, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community.

Other quality standards that should also be considered when commissioning and providing a high-quality service are listed in [related NICE quality standards](#).

Quality statement 1: Discussing concerns about possible dementia

Quality statement

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.

Rationale

Giving people the opportunity to discuss concerns about whether they, or someone they know, may have symptoms of dementia can help them make informed decisions about what steps they may want to take next.

Quality measure

Structure: Evidence of local arrangements to ensure 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.

What the quality statement means for each audience

People worried about possible dementia in themselves or someone they know can discuss their concerns, and what having dementia confirmed might mean, with someone with knowledge and expertise.

Local authorities and others commissioning services work with providers to ensure the services they commission have people with knowledge and expertise who can discuss concerns, and the options of seeking a diagnosis, with people worried about possible dementia in themselves or someone they know.

Organisations providing care and support ensure staff with knowledge and expertise can discuss with people worried about possible dementia in themselves or someone they know concerns and the options of seeking a diagnosis.

Social care and health care staff with knowledge and expertise ensure they give people worried about possible dementia in themselves or someone they know the opportunity to discuss concerns and the options of seeking a diagnosis.

Source guidance

Dignity in care (2006, updated 2013) SCIE guide 15, Communication

Data source

Structure: Local data collection.

Definitions

People with knowledge and expertise

This could include, but should not be limited to:

- GPs
- voluntary and community groups
- care home managers
- home care managers.

Equality and diversity considerations

Services should be aware of the special needs of younger people with dementia and people with learning disabilities (NICE guideline on dementia, recommendation 1.13.2 and NICE guideline on mental health problems in people with learning disabilities, recommendations 1.7.5 and 1.8.16).

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.

Social care and healthcare staff should identify the specific needs of people with dementia and their carers arising from diversity, including gender, sexuality, ethnicity, age and religion. These needs should be recorded in care plans and addressed (NICE guideline on dementia, recommendation 1.13.1).

Quality statement 2: Choice and control in decisions

Quality statement

People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.

Rationale

It is important to remember that people with dementia are often able to make decisions about their care and support. Choice and control in decisions can help ensure that the support provided reflects the preferences of people with dementia and helps them retain independence. If this is not possible, because of a decline in cognitive function and reduced capacity, services may need to provide additional support; input from carers or advocacy services may need to be sought to help with decision-making. When people with dementia lack capacity, decisions made on their behalf under the [Mental Capacity Act 2005](#) should be made in line with the accompanying code of practice.

Quality measure

Structure:

- a) Evidence of local arrangements to ensure that people with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.
- b) Evidence that decisions made under the [Mental Capacity Act 2005](#) on behalf of people with dementia are made in line with the code of practice that accompanies the Act.

Outcome:

- a) Feedback from people with dementia that they have choice and control in decisions affecting their care and support.
- b) Feedback from carers of people with dementia that the person they support has choice and control in decisions affecting their care and support.

What the quality statement means for each audience

People with dementia are involved in making choices and decisions about their care and support.

Carers of people with dementia are involved in supporting people with dementia to make choices and decisions about care and support.

Local authorities and others commissioning services work with providers to ensure the services they commission enable people with dementia, with the involvement of their carers, to have choice and control in decisions affecting their care and support.

Organisations providing care and support ensure people with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.

Social care and health care staff ensure people with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.

Source guidance

- [Personalisation – a rough guide](#) (2012) SCIE guide 47
- [Dignity in care](#) (2006, updated 2013) SCIE guide 15, Choice and control

Data source

Structure: a) and b) Local data collection.

Outcome: a) and b) Local data collection.

Definitions

Carers

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.

Decisions affecting care and support

This refers to decisions about the level and type of support provided, as well as personal decisions such as what to eat and when to go to bed. When people with dementia lack capacity, decisions made on their behalf under the [Mental Capacity Act 2005](#) should be made in line with the accompanying code of practice.

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.

Social care and healthcare staff should identify the specific needs of people with dementia and their carers arising from diversity, including gender, sexuality, ethnicity, age and religion. These needs should be recorded in care plans and addressed (NICE guideline on [dementia](#), recommendation 1.13.1).

Quality statement 3: Reviewing needs and preferences

Quality statement

People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change.

Rationale

The needs of people with dementia will change as their circumstances change. It is important their care and support adapts quickly to changes in circumstances, and a review should be triggered when changes happen. This can help ensure that appropriate care is provided at the right time to enable people to continue to live well with dementia.

Quality measure

Structure:

- a) Evidence of local arrangements to ensure that people with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change.
- b) Evidence that decisions made under the [Mental Capacity Act 2005](#) about needs and preferences of people with dementia are made in line with the code of practice that accompanies the Act.

Outcome:

- a) Feedback from people with dementia that they participate in a review of their needs and preferences when their circumstances change.
- b) Feedback from the carers of people with dementia that the person they support has their needs and preferences reviewed when their circumstances change.

What the quality statement means for each audience

People with dementia take part in a review of their needs and preferences when their circumstances change.

Carers of people with dementia are involved in helping the person they support participate in a review of their needs and preferences when circumstances change.

Local authorities and others commissioning services work with providers to ensure the services they commission enable people with dementia to participate, with the involvement of their carers, in a review of their needs and preferences when circumstances change.

Organisations providing care and support ensure people with dementia participate in a review of their needs and preferences, with the involvement of their carers, when circumstances change.

Social care and health care staff ensure people with dementia participate, with the involvement of their carers, in a review of their needs and preferences when circumstances change.

Source guidance

Dementia: assessment, management and support for people living with dementia and their carers (2018) NICE guideline 97, recommendations 1.3.2 and 1.12.2

Data source

Structure: a) and b) Local data collection.

Outcome: a) and b) Local data collection.

Definitions

Carers

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.

Review of needs and preferences

This refers to the actions taken to re-examine the support needs and preferences of a person with dementia and assess whether existing support is still appropriate or needs altering to address unmet needs or changes in preference. It can also apply to re-examining needs and preferences of people not currently receiving support but for whom circumstances have changed.

When circumstances change

This refers equally to changes experienced by people with dementia and changes experienced by their carers. This includes, but is not limited to, changes in:

- care and support needs
- behaviour
- mental health and wellbeing
- preferences
- personal circumstances.

When people with dementia lack capacity, review decisions made on their behalf under the [Mental Capacity Act 2005](#) should be made in line with the accompanying code of practice.

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.

Social care and healthcare staff should identify the specific needs of people with dementia and their carers arising from diversity, including gender, sexuality, ethnicity, age and religion. These needs should be recorded in care plans and addressed (NICE guideline on [dementia](#), recommendation 1.13.1).

Quality statement 4: Leisure activities of interest and choice

Quality statement

People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.

Rationale

It is important that people with dementia can take part in leisure activities during their day that are meaningful to them. People have different interests and preferences about how they wish to spend their time. People with dementia are no exception but increasingly need the support of others to participate. Understanding this and how to enable people with dementia to take part in leisure activities can help maintain and improve quality of life.

Quality measure

Structure:

- a) Evidence of local arrangements to find out about the individual interests and preferences of people with dementia in order to ensure access to leisure activities of interest.
- b) Evidence of local arrangements to ensure that people with dementia are enabled to take part in leisure activities during their day based on individual interest and choice.
- c) Evidence that when choices of activities during their day are made under the [Mental Capacity Act 2005](#) on behalf of people with dementia who lack capacity, they are made in line with the code of practice that accompanies the Act.

Outcome:

- a) Feedback from people with dementia that they take part in leisure activities during their day based on individual interest and choice.
- b) Feedback from the carers of people with dementia that the person they support takes part in leisure activities during their day based on individual interest and choice.

What the quality statement means for each audience

People with dementia can choose to take part in leisure activities, during their day, which match their interests.

Carers of people with dementia are involved in helping the person they support to choose and take part in leisure activities, during their day, which match the interests of the person with dementia.

Local authorities and others commissioning services work with providers to ensure the services they commission enable people with dementia, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.

Organisations providing care and support ensure people with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.

Social care staff enable people with dementia, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.

Source guidance

- [Dementia: assessment, management and support for people living with dementia and their carers \(2018\) NICE guideline 97, recommendation 1.4.1](#)
- [Personalisation – a rough guide \(2012\) SCIE guide 47](#)
- [Dignity in care \(2006, updated 2013\) SCIE guide 15, Choice and control](#)

Data source

Structure: a), b) and c) Local data collection.

Outcome: a) and b) Local data collection.

Definitions

Enabled

This refers to actions taken by care providers to ensure that people with dementia can take part in

leisure activities during their day. This includes, but is not limited to, finding out people's individual interests and preferences, providing daily activities and providing transport. When people with dementia lack capacity, decisions made on their behalf under the [Mental Capacity Act 2005](#) should be made in line with the accompanying code of practice.

Carers

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.

Leisure activities

Leisure activities such as shopping, reading and listening to music should reflect the interests of the person with dementia. Leisure activities are pleasurable activities, rather than activities of daily living such as personal care and attending to hygiene.

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.

Social care staff should identify the specific needs of people with dementia and their carers arising from diversity, including gender, sexuality, ethnicity, age and religion. These needs should be recorded in care plans and addressed (NICE guideline on [dementia](#), recommendation 1.13.1).

Quality statement 5: Maintaining and developing relationships

Quality statement

People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.

Rationale

The ability to maintain and develop personal and social relationships is important for a person's wellbeing. It is important that people with dementia continue to have opportunities to engage with friends and family, and to develop new relationships.

Quality measure

Structure: Evidence of local arrangements to ensure that people with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.

Outcome:

- a) Feedback from people with dementia that they are enabled to maintain and develop relationships.
- b) Feedback from the carers of people with dementia that the person they support is enabled to maintain and develop relationships.

What the quality statement means for each audience

People with dementia can continue to meet their friends and family and can make new relationships.

Carers of people with dementia are involved in helping the person they support to meet with their friends and family and make new relationships.

Local authorities and others commissioning services work with providers to ensure the services they commission enable people with dementia, with the involvement of their carers, to maintain and develop relationships.

Organisations providing care and support ensure people with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.

Source guidance

- Dementia: assessment, management and support for people living with dementia and their carers (2018) NICE guideline 97, recommendation 1.13.1
- Personalisation – a rough guide (2012) SCIE guide 47
- Dignity in care (2006, updated 2013) SCIE guide 15, Social inclusion
- Dignity in care (2006, updated 2013) SCIE guide 15, Choice and control

Data source

Structure: Local data collection.

Outcome: a) and b) Local data collection.

Definitions

Enabled

This refers to actions taken by care providers to ensure that people with dementia can maintain and develop relationships. This includes, but is not limited to, providing transport to social events, and providing a suitable setting for friends and family to visit and socialise with people in residential care settings. People with dementia may face particular difficulties when engaging with others, such as communication difficulties, and may need skilled support to maintain and develop relationships. This could be provided by family and friends or paid staff. The skill lies in understanding the difficulties people have in engaging, and knowing how to address these.

Carers

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.

Relationships

This refers to ongoing contact with friends and family, and the opportunity to develop new social contacts beyond the immediate vicinity of the care facility or other accommodation.

Equality and diversity considerations

Social care staff should identify the specific needs of people with dementia and their carers arising from diversity, including gender, sexuality, ethnicity, age and religion. These needs should be recorded in care plans and addressed (NICE guideline on [dementia](#), recommendation 1.13.1).

Quality statement 6: Physical and mental health and wellbeing

Quality statement

People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

Rationale

People with dementia are not always in a position to seek help or advice about other issues that could be affecting their health and wellbeing. Therefore it is important that they are enabled to access services where routine screening and other assessments can take place.

Quality measure

Structure: Evidence of local arrangements to ensure that people with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

Outcome:

- a) Feedback from people with dementia that they are enabled to access services that help maintain their physical and mental health and wellbeing.
- b) Feedback from the carers of people with dementia that the person they support is enabled to access services that help maintain their physical and mental health and wellbeing.

What the quality statement means for each audience

People with dementia can have routine check-ups of their physical and mental health and can see healthcare professionals when they have concerns.

Carers of people with dementia are involved in helping the person they support have routine physical and mental health check-ups and see healthcare professionals when they have concerns.

Local authorities and other commissioning services work with providers to ensure the services they commission enable people with dementia, with the involvement of their carers, to have routine check-ups of their physical and mental health and see healthcare professionals when they have

concerns.

Organisations providing care and support ensure people with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

Social care and health care staff enable people with dementia, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

Source guidance

- [Dementia: assessment, management and support for people living with dementia and their carers \(2018\) NICE guideline 97, recommendations 1.3.2 and 1.8.1](#)
- [Dignity in care \(2006, updated 2013\) SCIE guide 15, Pain management](#)
- [Dignity in care \(2006, updated 2013\) SCIE guide 15, Eating and nutritional care](#)

Data source

Structure: Local data collection.

Outcome: a) and b) Local data collection.

Definitions

Enabled

This refers to local protocols and the specific actions contained in those protocols that ensure people with dementia have routine check-ups of their physical and mental health and wellbeing, and have access to services when they have concerns about their physical or mental health.

Carers

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.

Services that help maintain physical and mental health and wellbeing

Examples of services that help maintain physical and mental health and wellbeing include:

- general practice
- occupational therapy services
- Admiral nurses
- community palliative care
- health promotion services, including smoking cessation
- mental health teams
- opticians
- hearing therapists
- dentists
- chiropodists
- physiotherapy services.

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.

Social care and healthcare staff should identify the specific needs of people with dementia and their carers arising from diversity, including gender, sexuality, ethnicity, age and religion. These needs should be recorded in care plans and addressed (NICE guideline on [dementia](#), recommendation 1.13.1).

Quality statement 7: Design and adaptation of housing

Quality statement

People with dementia live in housing that meets their specific needs.

Rationale

Housing can be designed or adapted in a way that helps people with dementia manage their surroundings, retain their independence, and reduce feelings of confusion and anxiety.

Quality measure

Structure:

- a) Evidence of local arrangements to ensure that staff are trained to recognise when adaptations to housing can help meet the specific needs of people with dementia.
- b) Evidence of local arrangements to ensure that new housing for people with dementia is designed to meet their specific needs.

Process:

- a) Proportion of people with dementia and receiving care at home whose housing has been adapted to meet their specific needs.

Numerator – the number of people in the denominator whose housing has been adapted to meet their specific needs.

Denominator – the number of people with dementia and receiving care at home.

- b) Proportion of care homes designed or adapted to meet the specific needs of people with dementia.

Numerator – the number of care homes designed or adapted to meet the specific needs of people with dementia.

Denominator – the number of care homes with people with dementia.

c) Proportion of extra-care housing that has been designed or adapted to meet the specific needs of people with dementia.

Numerator – the number of extra-care housing units that have been designed or adapted to meet the specific needs of people with dementia.

Denominator – the number of extra-care housing units.

d) Proportion of sheltered housing that has been designed or adapted to meet the specific needs of people with dementia.

Numerator – the number of sheltered housing units that have been designed or adapted to meet the specific needs of people with dementia.

Denominator – the number of sheltered housing units.

Outcome:

a) Feedback from people with dementia that their housing has been adapted to meet their specific needs.

b) Feedback from the carers of people with dementia that the person they support has had their housing adapted to meet their specific needs.

What the quality statement means for each audience

People with dementia live in housing that is adapted to help them maintain their independence.

Carers of people with dementia are involved in helping to identify how the housing of the person they support may be adapted to help maintain their independence.

Local authorities and other commissioning services work with providers to ensure the housing they commission is designed or adapted to meet the specific needs of people with dementia and also commission services that can adapt the homes of people with dementia to better meet their specific needs.

Organisations providing care and support ensure housing is designed or adapted to meet the specific needs of people with dementia.

Socialcare staff ensure housing meets the specific needs of people with dementia.

Source guidance

- [Personalisation – a rough guide](#) (2012) SCIE guide 47
- [Dignity in care](#) (2006, updated 2013) SCIE guide 15, Practical assistance

Data source

Structure: a) and b) Local data collection.

Process: a), b), c) and d) Local data collection.

Outcome: a) and b) Local data collection.

Definitions

Housing

This statement applies equally to people with dementia receiving care in their own homes or living in residential or care homes.

Design and adaptation

The design and adaptation of housing to help meet the needs of people with dementia could include changes to and use of:

- lighting
- colour schemes
- floor coverings
- assistive technology
- signage
- wide doorways
- flat gardens, low-wall flower beds

- glass-fronted cupboard doors in kitchens so people can see what is inside
- memory cues
- colour contrasts
- minimising reflections and glare
- notice boards.

Further suggestions are included in the King's Fund document [Developing supportive design for people with dementia](#). Any adaptation should take into account the preferences of the person with dementia.

Extra-care housing

There is some local variance in the specific features of extra-care housing. The National Dementia Strategy implementation group produced a [commissioning guide for extra care housing and dementia](#) which describes extra-care housing as including the following features:

- Care and support available to occupants around the clock.
- Sheltered housing, not residential care. Occupants live in their own homes, have security of tenure via assured tenancy or lease, and can determine who comes into their homes and who delivers their support plan.
- Often purpose built to Home For Life standards, and often includes a range of communal facilities.
- Some aspects of Extra Care such as housing design and management are covered by housing legislation, regulations and standards, and other aspects, for example, care provision, by the non-residential community care framework and care registration requirements.

Sheltered housing

[NHS Choices](#) describes sheltered housing as including the following features:

- Aimed at people over 60 years of age, although some schemes are available for over 55s.
- Self-contained, purpose-built flats, houses or bungalows with their own front doors, kitchens and bathrooms.

- Available for couples or single people and offering independent living with extra help if needed.
- Run by scheme managers or wardens who may live on the site or work office hours. The scheme manager is there to help arrange suitable support for residents, to manage any repair work on the properties and to help out in emergencies.
- Access to 24-hour emergency care assistance via an alarm system linked to a monitoring centre, which will contact a family member, GP or emergency service if needed.

Equality and diversity considerations

Social care and healthcare staff should identify the specific needs of people with dementia and their carers arising from diversity, including gender, sexuality, ethnicity, age and religion. These needs should be recorded in care plans and addressed (NICE guideline on [dementia](#), recommendation 1.13.1).

Quality statement 8: Planning and evaluating services

Quality statement

People with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.

Rationale

Person-centred services need to ensure that the people using them have opportunities to shape how services are delivered, what improvements should be made and how best to make those improvements.

Quality measure

Structure: Evidence of local arrangements to ensure people with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.

Outcome:

- a) Feedback from people with dementia that they participate in the design, planning, evaluation and delivery of services.
- b) Feedback from the carers of people with dementia that the person they support participates in the design, planning, evaluation and delivery of services.

What the quality statement means for each audience

People with dementia are given the opportunity to be involved in and influence the design, planning, evaluation and delivery of services.

Carers of people with dementia help the person they support to participate in and influence the design, planning, evaluation and delivery of services.

Local authorities and others commissioning services work with providers to ensure the services they commission give people with dementia, with the involvement of their carers, opportunities to participate in and influence the design, planning, evaluation and delivery of services.

Organisations providing care and support ensure people with dementia are given, with the involvement of their carers, opportunities to participate in and influence the design, planning, evaluation and delivery of services.

Social care and health care staff ensure they give people with dementia, with the involvement of their carers, opportunities to participate in and influence the design, planning, evaluation and delivery of services.

Source guidance

- [Dementia: assessment, management and support for people living with dementia and their carers](#) (2018) NICE guideline 97, recommendations 1.1.1, 1.3.6 and 1.13.3.
- [Dignity in care](#) (2006, updated 2013) SCIE guide 15, Choice and control.

Data source

Structure: Local data collection.

Outcome: a) and b) Local data collection.

Definitions

Carers

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.

Participate and influence

In this statement, 'participate and influence' refers to people having opportunities to participate in initiatives and also being able to influence how the initiatives are delivered. For example, people with dementia should participate in a service evaluation, but also should have opportunities to influence how the evaluation is conducted and what aspects of a service are being evaluated and what a positive outcome should be.

Equality and diversity considerations

Social care and healthcare staff should identify the specific needs of people with dementia and their carers arising from diversity, including gender, sexuality, ethnicity, age and religion. These needs should be recorded in care plans and addressed (NICE guideline on [dementia](#), recommendation 1.13.1).

Quality statement 9: Independent advocacy

Quality statement

People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.

Rationale

When significant decisions are being made concerning the current and future care of someone with dementia, it is important that they can access independent advocacy services if they are not fully able to present their own views.

Quality measure

Structure:

- a) Evidence of local arrangements to ensure that people with dementia are enabled, with the involvement of their carers, to access independent advocacy services.
- b) Evidence of proactive approaches to reach people with dementia who may have difficulty accessing advocacy services.
- c) Evidence that people with dementia supported under the [Mental Capacity Act 2005](#) are provided with access to advocacy in line with the code of practice that accompanies the Act.

Process: Proportion of people with dementia accessing independent advocacy services.

Numerator – the number of people in the denominator accessing independent advocacy services.

Denominator – the number of people with dementia.

Outcome:

- a) Feedback from people with dementia that they have been enabled to access independent advocacy services.
- b) Feedback from the carers of people with dementia that the person they support was enabled to

access independent advocacy services.

What the quality statement means for each audience

People with dementia can have help from independent advocacy services to present their views.

Carers of people with dementia are involved in helping the person they support to access independent advocacy services to present their views.

Local authorities and others commissioning services work with providers to ensure the services they commission enable people with dementia, with the involvement of their carers, to access independent advocacy services.

Organisations providing care and support ensure people with dementia are enabled, with the involvement of their carers, to access independent advocacy services.

Social care and health care staff ensure they enable people with dementia, with the involvement of their carers, to access independent advocacy services.

Source guidance

- [Dementia: assessment, management and support for people living with dementia and their carers \(2018\) NICE guideline 97, recommendations 1.1.6 and 1.3.2](#)
- [Personalisation – a rough guide \(2012\) SCIE guide 47](#)
- [IMCA and paid relevant person's representative roles in the Mental Capacity Act Deprivation of Liberty Safeguards \(2011, updated 2017\) SCIE guide 41](#)
- [Independent Mental Capacity Advocate involvement in accommodation decisions and care reviews \(2010\) SCIE guide 39](#)
- [Practice guidance on the involvement of Independent Mental Capacity Advocates \(IMCAs\) in safeguarding adults \(2009\) SCIE guide 32](#)
- [Commissioning and monitoring of Independent Mental Capacity Advocate \(IMCA\) services \(2009, updated 2010\) SCIE guide 31](#)
- [Dignity in care \(2006, updated 2013\) SCIE guide 15, Choice and control](#)

Data source

Structure: a), b) and c) Local data collection.

Process: Local data collection.

Outcome: a) and b) Local data collection.

Definitions

Enabled

This refers to local protocols and specific actions contained in those protocols that ensure people with dementia can access independent advocacy services.

Carers

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.

Independent advocacy services

Action for Advocacy states '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 represent their views. Advocacy promotes social inclusion, equality and social justice.' This includes instructed advocacy and non-instructed advocacy for people who do not have capacity to instruct advocacy services on their own behalf. A non-instructed advocate seeks to uphold the person's rights; ensure fair and equal treatment and access to services; and make certain that decisions are taken with due consideration for all relevant factors, which must include the person's unique preferences and perspectives.

Independent advocacy services include, but are not limited to:

- independent mental capacity advocates provided under the Mental Capacity Act 2005
- relevant local user groups
- charitable organisations.

When people with dementia lack capacity, decisions made on their behalf under the [Mental Capacity Act 2005](#) should be made in line with the accompanying code of practice.

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.

Social care and healthcare staff should identify the specific needs of people with dementia and their carers arising from diversity, including gender, sexuality, ethnicity, age and religion. These needs should be recorded in care plans and addressed (NICE guideline on [dementia](#), recommendation 1.13.1).

Quality statement 10: Involvement and contribution to the community

Quality statement

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

Rationale

Giving people with dementia opportunities to be involved in and make a positive contribution to their community supports their ongoing independence, helps maintain their dignity and therefore can substantially improve their feelings of wellbeing.

Quality measure

Structure: Evidence of local arrangements to ensure that people with dementia are enabled, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community.

Outcome:

- a) Feedback from people with dementia that they have been able to maintain and develop their involvement in and contribution to their community.
- b) Feedback from the carers of people with dementia that the person they support has been able to maintain and develop their involvement in and contribution to their community.

What the quality statement means for each audience

People with dementia can continue to be involved in and contribute to their community.

Carers of people with dementia are involved in helping the person they support to continue to be involved in and contribute to their community.

Local authorities and others commissioning services work with providers to ensure the services they commission enable people with dementia, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community.

Organisations providing care and support enable people with dementia, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community.

Social care staff enable people with dementia, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community.

Source guidance

- [Personalisation – a rough guide](#) (2012) SCIE guide 47
- [Dignity in care](#) (2006, updated 2013) SCIE guide 15, Social inclusion

Data source

Structure: Local data collection.

Outcome: a) and b) Local data collection.

Definitions

Enabled

This refers to local protocols and specific actions contained in those protocols that make sure people with dementia are able to retain contact with their community. Examples of such actions include:

- helping people to attend community events
- helping people to take part in community activities
- helping people to continue everyday activities such as going to shops that they enjoy shopping in
- supporting people to participate as volunteers in community projects
- promoting peer support and helping people with dementia to offer advice and pass on tips to those in a similar situation
- supporting people to continue to vote if they wish to
- helping people to participate in sponsored events and raise money for other causes

- helping people to participate in intergenerational projects, for example, history projects and telling local school children about their experiences in years gone by or teaching children to knit
- encouraging people to talk about their experience of having dementia to local groups, organisations or businesses, and raise awareness of how others can help.

Carers

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.

Equality and diversity considerations

Social care and healthcare staff should identify the specific needs of people with dementia and their carers arising from diversity, including gender, sexuality, ethnicity, age and religion. These needs should be recorded in care plans and addressed (NICE guideline on [dementia](#) recommendation 1.13.1).

Using the quality standard

It is important that the quality standard is considered alongside current policy and guidance documents listed in [development sources](#).

NICE quality standards are not mandatory. They can be used for a wide range of purposes both locally and nationally, to improve outcomes, including to:

- improve quality in practice and outcomes
- support the provision of care that has been shown to work and to be cost effective
- increase the national consistency of social care provision
- support the development of inter-agency and inter-professional working.
- demonstrate to people with dementia what they can expect from high-quality care.

[Information for the public](#) about the quality standard is also available.

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care for people 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. Quality standards are intended to drive up the quality of care, so achievement levels of 100% should be aspired to for quantitative measures where numerators and denominators are given. However, NICE recognises that this may not always be appropriate in practice when taking account of safety, choice and professional judgement and so desired levels of achievement should be defined locally.

For further information, including guidance on using quality measures, please see [how to use quality standards](#).

Diversity, equality and language

During the development of this quality standard, equality issues have been considered and [equality assessments](#) are published on the NICE website.

Good communication between social care and healthcare services and people 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 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.

Development sources

Evidence sources

The documents below contain recommendations that were used by the topic expert group to develop the quality standard.

- NICE (2018) [Dementia: assessment, management and support for people living with dementia and their carers](#). NICE guideline NG97
- Social Care Institute for Excellence (2012) [Personalisation: a rough guide](#). SCIE guide 47
- Social Care Institute for Excellence (2011, updated 2017) [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) [Independent mental capacity advocate involvement in accommodation decisions and care reviews](#). SCIE guide 39
- 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, updated 2010) [Commissioning and monitoring of Independent Mental Capacity Advocate \(IMCA\) services](#). SCIE guide 31
- Social Care Institute for Excellence (2006, updated 2013) [Dignity in care](#). SCIE guide 15
- Social Care Institute for Excellence (2005, updated 2007) [Implementing the Carers \(Equal Opportunities\) Act 2004](#). SCIE guide 9

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 quality in 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](#)
- 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](#)

Definitions and data sources for the quality measures

References included in the definitions and data sources sections:

- [NHS Choices](#)
- King's Fund (2013) [Developing supportive design for people living with dementia](#)
- National Dementia Strategy implementation group (2010) [Commissioning guide for extra care housing and dementia](#)
- Ministry of Justice (2005) [Mental Capacity Act Code of Practice](#)

Related NICE quality standards

- [Patient experience in adult NHS services \(2011\)](#) NICE quality standard 15
- [End of life care for adults \(2011, updated 2017\)](#) NICE quality standard 13
- [Dementia: support in health and social care \(2010\)](#) NICE quality standard 1

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Update information

Minor changes since publication

June 2018: Changes have been made to align this quality standard with the updated NICE guideline on [dementia](#). References and source guidance sections have been updated.

About this quality standard

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 [development sources](#), along with relevant policy context, definitions and data sources.

This quality standard was produced collaboratively with representatives from social care and the NHS, along with their partners, people with dementia and carers.

This quality standard has been incorporated into the NICE Pathway on [dementia](#).

We have produced a [summary for service users and carers](#).

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Endorsing organisation

This quality standard has been endorsed by Department of Health and Social Care, as required by the Health and Social Care Act (2012)

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- [British Association for Counselling and Psychotherapy](#)
- [Compassion in Dying](#)
- [Royal College of Occupational Therapists](#)
- [English Community Care Association](#)
- [National Care Forum](#)
- [AGILE: Chartered Physiotherapists working with older people](#)
- [Skills for Care](#)
- [Voluntary Organisations Disability Group](#)
- [College of Mental Health Pharmacy](#)
- [United Kingdom Homecare Association](#)
- [Dementia Advocacy Network](#)
- [Stonewall](#)

- [Social Care Institute for Excellence](#)
- [Sue Ryder](#)
- [Association of Directors of Adult Social Services](#)
- [Faculty of General Dental Practice](#)