

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

HEALTH AND SOCIAL CARE

QUALITY STANDARDS PROGRAMME

Social care quality standard: Care of people with dementia

Output: Briefing paper

Introduction

In March 2012, a draft social care quality standard scope was published for consultation. Recommendations from the agreed evidence sources have been prioritised against the key areas highlighted in the draft scope (see separate paper). This briefing paper presents proposed quality statements along with supporting evidence reviewed against the three dimensions of quality: effectiveness, experience and safeguarding/safety. Information is provided on available cost-effectiveness evidence and current practice for the proposed standard. Where possible, evidence from the source guideline is presented. When this is not available, other evidence sources have been used. The draft quality statements and measures presented in this paper are based on published recommendations from the following key development sources:

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

SCIE guide 15 (2010) [Dignity in care](#).

SCIE guide 39 (2010) [Independent Mental Capacity Advocate involvement in accommodation decisions and care reviews](#).

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

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

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

SCIE report 20 (2010) [Personalisation: a rough guide](#).

SCIE guide 9 (2007) [Implementing the Carers \(equal Opportunities\) Act 2004](#).

1 Assessment and diagnosis – Recognising and responding to the symptoms of sensory loss, cognitive impairment and possible dementia + Recognising the symptoms of dementia in younger people

1.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	NICE CG42 1.1.9.1, 1.1.1.1 and 1.1.3.1 Please see page 2 of the prioritisation paper
Proposed quality statement	Staff are appropriately trained in recognising the signs and symptoms of memory loss, cognitive impairment and possible dementia.
Draft quality measure	<p>Structure: Evidence of local arrangements to provide an appropriate training programme for staff, on the signs and symptoms of memory loss, cognitive impairment and possible dementia.</p> <p>Process: Proportion of staff, trained in recognising the signs and symptoms of memory loss, cognitive impairment and possible dementia.</p> <p>Numerator – the number of staff in the denominator who are trained in recognising the signs and symptoms of memory loss, cognitive impairment and possible dementia.</p> <p>Denominator – the number of staff.</p> <p>Outcome: Evidence that staff feel competent in recognising the signs of possible dementia.</p>
Definitions	<p>Training programmes should account for different signs and symptoms in different types of people being cared. For example, younger people with learning disabilities may have different signs and symptoms than older people.</p> <p>Appropriate training competencies are detailed by the 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.</p>

Guidance recommendations	NICE CG42 1.3.3.1 Please see page 2 of the prioritisation paper
Proposed quality statement	People with symptoms of sensory loss, cognitive impairment or possible dementia are considered for referral to a memory assessment service.
Draft quality measure	Structure: Evidence of local arrangements to ensure procedures are in place on referring people with symptoms of sensory loss, cognitive impairment or possible dementia to a

	<p>memory assessment service.</p> <p>Process: Proportion of people with signs and symptoms of sensory loss, cognitive impairment and possible dementia that are considered for referral to a memory assessment service.</p> <p>Numerator – the number of people in the denominator who are considered for referral to a memory assessment service.</p> <p>Denominator – the number of people with signs and symptoms of sensory loss, cognitive impairment and possible dementia.</p>
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1.1.2 Effectiveness evidence

Evaluating the effects of training programmes in dementia care is a challenging task. The developers of NICE clinical guideline 42 examined cluster randomised trials. Training programmes that teach specific skills (such as the STAR programme) in the workplace, and which build in managerial support, do seem to be associated with positive outcomes. Changes in staff behaviour (for example, avoiding use of restraints and reducing medication use) may be easier to achieve than changes in residents' patterns of behaviour and function but are, arguably, an important part of enhancing quality of care and well-being. Input to care homes from multidisciplinary teams providing training, support and advice on management of residents is associated with favourable outcomes.

The developers of NICE clinical guideline 42 also considered eight sources of qualitative evidence on the experiences of people with dementia and their carers that have some relevance to staff training. Qualitative evidence points to the potential value of input from carers into staff training and identifies particular staff training needs in relation to communicating with people with dementia and understanding their perspective, and also involving and understanding the perspective of carers.

NICE clinical guideline 42 recommendation 1.1.3.1 on training in dementia awareness for people working with younger people at risk of dementia, is based on dementia prevalence data. People with Down's syndrome are at risk of developing Alzheimer's disease about 30–40 years earlier than the rest of the population, although lifetime risk may not be different. The prevalence of dementia in people with learning disabilities without Down's syndrome is generally found to be two or three times that expected in people over 65.

NICE clinical guideline 42 recommendation 1.3.3.1 on referral to memory assessments services derives from evidence that early recognition and active therapy delays the subsequent need for nursing home care and reduces the risk of misdiagnosis and inappropriate management. There is insufficient evidence of benefit to justify population screening in primary care.

1.1.3 User experience of services

Desired outcomes for people with dementia were described in the National Dementia Declaration¹. These included:

- I have received an early diagnosis which was sensitively communicated.

The Alzheimer's Society report Dementia 2012², found that in a survey of people with dementia living at home:

- One third (31%) of people with dementia said that they struggled to get a diagnosis. (It is important to note that respondents to the survey are in touch with Alzheimer's Society and therefore more likely to have received a diagnosis and to be receiving support.)
- 68% of respondents had a gap of longer than a year between noticing their symptoms and getting a diagnosis. 8% of respondents had to wait five years or over for a diagnosis.

1.1.4 Safety/safeguarding

No specific safety or safeguarding issues identified.

1.1.5 Current practice

Markers of appropriate training are contained within the Department of Health's 'Common core principles for supporting people with dementia'³:

- Principle 1 Know the early signs of dementia
- Principle 2 Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stage.
- Principle 7 Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia.

Contained within the National Dementia Strategy⁴:

- Objective 2 Good quality early diagnosis and intervention for all.
- Objective 13 An informed and effective workforce for people with dementia.

In investigating where the National Dementia Strategy funding had been spent, the All-Party Parliamentary Group⁵ found two thirds of PCTs questioned had not allocated funding or failed to provide evidence of doing so.

¹ Dementia Action Alliance (2010) [National dementia declaration](#)

² Alzheimer's Society (2012) [Dementia 2012: a national challenge](#)

³ 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](#).

⁴ Department of Health (2009) [National Dementia Strategy](#)

⁵ All-Party Parliamentary Group on Dementia (2010) [A misspent opportunity?: inquiry into the funding of the National Dementia Strategy](#)

Of those that did the most common priority area was memory assessment and early diagnosis. Few PCTS explicitly mentioned workforce development.

The National Audit of Dementia⁶ reports that only 5% of hospitals had mandatory training in awareness of dementia for all staff, and 23% of hospitals had a training and knowledge framework or strategy identifying the necessary skill development in working with and caring for people with dementia. 32% of staff said they had sufficient training/learning and development in dementia care, including awareness training and skills based training.

A GP survey by the National Audit Office⁷ found that:

- 47% of GPs felt they had received sufficient basic and post-qualifying training to help me diagnose dementia. n increase from 31% in 2006.
- 80% of GPs felt it important to look actively for early signs of dementia. This is an increase from 62% in 2006.
- 77% of GPs felt it is beneficial to make an early diagnosis of dementia. This is an increase from 68% in 2006.

Key messages from SCIE research briefing 35⁸ include:

- Lower levels of awareness about dementia and the existence of stigma within BME communities help explain why BME people are currently under-represented in dementia services.
- Staff working in dementia services would like more training on how to give culturally acceptable care and support to BME people with dementia.

SCIE Guide 35⁹ details the legislative framework provided by the Equality Act, including a ban on age discrimination against adults in the provision of services and exercise of public functions. It further recommends taking appropriate action over age discrimination affecting younger people, including disabled young people making the transition to receiving support from adult services, working age adults, and younger groups within the population of older people.

1.1.6 Current indicators

None identified.

⁶ Royal College of Psychiatrists (2011) [Report of the National Audit of Dementia Care in General Hospitals](#)

⁷ National Audit Office (2010) [Improving dementia services in England - an interim report](#)

⁸ SCIE (2011) [Research briefing 35: Black and minority ethnic people with dementia and their access to support and services](#)

⁹ SCIE (2010) [Age equality and age discrimination in social care: An interim practice guide.](#) SCIE Guide 35.

2 Assessment and diagnosis – Experience and concerns of people with symptoms suggestive of dementia

2.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	SCIE Guide 15 Please see page 3 of the prioritisation paper
Proposed quality statement	People with concerns about possible dementia feel staff listen to them and address their concerns.
Draft quality measure	Outcome: Evidence that people with concerns about possible dementia feel listened to and have their concerns addressed.

2.1.2 Effectiveness evidence

The developers of SCIE Guide 15 highlighted that older people want to be cared for by staff who are patient, take time to listen to them, and do not rush their care.

2.1.3 User experience of services

Desired outcomes for people with dementia were described in the National Dementia Declaration¹⁰. These included:

- I am listened to and have my views considered, from the point I was first worried about my memory.

2.1.4 Safety/safeguarding

No safety or safeguarding issues identified.

2.1.5 Current practice

Markers of appropriate training are contained within the Department of Health's 'Common core principles for supporting people with dementia'¹¹:

- Principle 3 Communicate sensitively to support meaningful interaction.

2.1.6 Current indicators

None identified.

¹⁰ Dementia Action Alliance (2010) [National dementia declaration](#)

¹¹ 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](#).

3 Assessment and diagnosis – Sharing information about the diagnosis with relevant family members, carers and friends.

3.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	NICE CG42 1.4.1.2 Please see page 4 of the prioritisation paper
Proposed quality statement	People assessed for possible dementia are asked if they wish to know the diagnosis and with whom this should be shared.
Draft quality measure	Structure: Evidence of local arrangements to ensure that people assessed for possible dementia are asked if they wish to know the diagnosis and with whom this should be shared. Outcome: Evidence that people with dementia feel their wishes were upheld about knowing and sharing the diagnosis.

Guidance recommendations	NICE CG42 1.4.6.2, 1.4.6.1 and 1.1.5.1 Please see page 4 of the prioritisation paper
Proposed quality statement	People diagnosed with dementia, and their carers, are given written information about the condition and local support services, and referred to their local authority for a community care needs and eligibility assessment.
Draft quality measure	Structure: a) Evidence of local arrangements to provide people diagnosed with dementia and their carers with written information on the condition and local support services. b) Evidence of local protocols to refer people diagnosed with dementia to their local authority for a community care needs and eligibility assessment. Process: a) Proportion of people diagnosed with dementia, and their carers, given written information on their condition and the local support services. Numerator – the number of people in the denominator who are given written information on their condition and the local support services. Denominator – the number of people diagnosed with dementia and their carers. b) Proportion of people diagnosed with dementia referred to their local authority for a community care needs and eligibility assessment. Numerator – the number of people in the denominator who are

	<p>referred to their local authority for a community care needs and eligibility assessment.</p> <p>Denominator – the number of people diagnosed with dementia.</p> <p>Outcome: Evidence that people diagnosed with dementia and their carers feel they understand the condition and know how to contact local support services.</p>
Definitions	<p>NICE CG42 recommendation 1.4.6.2 states that written information should include:</p> <ul style="list-style-type: none"> • the signs and symptoms of dementia • the course and prognosis of the condition • treatments • local care and support services • support groups • sources of financial and legal advice, and advocacy • medico-legal issues, including driving • local information sources, including libraries and voluntary organisations.

3.1.2 Effectiveness evidence

Evidence examined in the development of NICE clinical guideline 42 found the majority of people with mild dementia wish to know of their diagnosis, and all practitioners should assume that the diagnosis will be discussed with the person with dementia, unless there are clear reasons not to do so. The benefits of sharing a diagnosis include ending uncertainty, confirming suspicions, increasing understanding of problems, giving access to support, promoting positive coping strategies, facilitating planning and fulfilment of short-term goals.

A systematic review on sharing the diagnosis of dementia suggests that non-sharing of information or vague information about it is confusing, upsetting and difficult for some people with dementia and their families.

Findings from primary research examined by the developers of NICE clinical guideline 42, indicate that better informed carers have lower depression but not lower anxiety or better physical health. The findings suggest that information and knowledge can decrease the risk of depression in carers, and that educational interventions and the provision of information for carers at an early stage are therefore potentially beneficial and important, although it is noted that it is important to watch for carers' raised anxiety.

The primary research also found that carers wanted information at the time of diagnosis in order to be forewarned. Findings indicated carers wanted both verbal and written – but not electronic – information from several sources.

3.1.3 User experience of services

The developers of NICE clinical guideline 42 considered qualitative evidence on accessing memory services. People reported that their visits to the memory assessment service can also be quite an ordeal. The doctor may speak to the carer separately from the person being assessed, leading to suspicion about what is being said. The assessment process itself may prove embarrassing, even humiliating. People report that they are aware that some of the questions are simple and feel foolish that they are unable to answer.

The developers of NICE clinical guideline 42 also considered qualitative evidence on the experience of receiving a diagnosis. Sensitivity is required in ensuring that information about the diagnosis is given in a way that is easily understood by the person concerned and acceptable to the family. Gentle questioning at an early stage will help to ascertain what people can, and want, to be told. They reported that much we can be learned from earlier work on sharing the diagnosis with people with cancer. It is especially important to be aware of different cultural sensitivities and the stigma that dementia holds for many people. This can range from subjective feelings of shame to a real exclusion from community and family life. Age and ethnicity are both factors in the sense of stigma associated with a diagnosis of dementia.

Desired outcomes for people with dementia were described in the National Dementia Declaration¹². These included:

- I have received an early diagnosis which was sensitively communicated.
- It's not a problem getting information and advice, including information about the range of benefits I can access to help me afford and cope with living at home.
- I know where I can get the information I need when I need it, and I can digest and re-digest it in a way that suits me.
- I have enough information and advice to make decisions about managing, now and in the future, as my dementia progresses.
- My carer has access to further information relevant to them, and understands which benefits they are also entitled to.

The Alzheimer's Society report Dementia 2012¹³, found that in a survey of people with dementia living at home:

- 32% of surveyed respondents reported that they were receiving some but not enough information about their condition and 6% reported that they had not received any information. 27% of respondents also reported that they had received some but not enough information to plan for the future and 19% said that they had not received enough

¹² Dementia Action Alliance (2010) [National dementia declaration](#)

¹³ Alzheimer's Society (2012) [Dementia 2012: a national challenge](#)

3.1.4 Safety/safeguarding

No specific safety or safeguarding issues identified.

3.1.5 Current practice

Markers of appropriate training are contained within the Department of Health's 'Common core principles for supporting people with dementia'¹⁴:

- Principle 3 Communicate sensitively to support meaningful interaction.
- Principle 6 Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice.

Contained with the National Dementia Strategy¹⁵:

- Objective 3 Good quality information for those with diagnosed dementia and their carers
- Objective 4 Enabling easy access to care, support and advice following diagnosis.

A GP survey by the National Audit Office¹⁶ found that:

- 78% of GPs felt providing a patient with a diagnosis is usually more helpful than harmful. This is an increase from 58% in 2006.
- Less than 40% of GPs felt families would rather be told about their relative's dementia as early as possible.

3.1.6 Current indicators

Data capturing the number of clients receiving services is collated by the RAP collection¹⁷. These tables include data on dementia clients.

P1- Number of clients receiving services provided or commissioned by the CASSR during the period, by age group, primary client type and service type

P2f - Number of clients receiving community based services or commissioned by the CASSR during the period, by age group, primary client type, and components of service

P2s - Number of clients receiving community based services or commissioned by the CASSR on the last day of the period, by age group, primary client type, and components of service.

¹⁴ 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](#).

¹⁵ Department of Health (2009) [National Dementia Strategy](#)

¹⁶ National Audit Office (2010) [Improving dementia services in England - an interim report](#)

¹⁷ The Information Centre for Health and Social Care available via www.ic.nhs.uk

4 Personalised care - Opportunities for people with dementia to discuss, make and revisit decisions about the future, their care and the associated risks, possibilities and implications

4.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	NICE CG42 1.1.4.4 Please see page 5 of the prioritisation paper
Proposed quality statement	People with dementia can discuss and revisit decisions about their current and future care.
Draft quality measure	<p>Structure:</p> <p>a) Evidence of local arrangements to provide [regular] opportunities for people with dementia to discuss and revisit decisions about their current and future care.</p> <p>b) Evidence of local arrangements to ensure discussions about current and future care are responsive to the needs of the service user.</p> <p>Process: Proportion of people with dementia given [regular] opportunities to discuss and revisit decisions about current and future care.</p> <p>Numerator – the number of people in the denominator given [regular] opportunities to discuss and revisit decisions about current and future care.</p> <p>Denominator – the number of people with dementia.</p> <p>Outcome: Evidence that people with dementia feel they can discuss and revisit decisions about their current and future care.</p>

4.1.2 Effectiveness evidence

NICE clinical guideline 42 recommendation 1.1.4.4 is based on consensus of opinion and the current legal framework.

4.1.3 User experience of services

Desired outcomes for people with dementia were described in the National Dementia Declaration¹⁸. These included:

- I can make decisions now about the care I want in my later life.

¹⁸ Dementia Action Alliance (2010) [National dementia declaration](#)

4.1.4 Safety/safeguarding

SCIE 'at a glance 33'¹⁹ emphasises the requirement in the Mental Capacity Act that a person should make their own decisions and where this is not possible because they lack the mental capacity to do so, that they should play a big a role as possible in decision-making processes that directly affect them. It must be assumed that a person has capacity to make a specific decision unless it is demonstrated that they are unable to do so

4.1.5 Current practice

Markers of appropriate training are contained within the Department of Health's 'Common core principles for supporting people with dementia'²⁰:

- Principle 4 Promote independence and encourage activity.

The National Audit of Dementia²¹ reports that training in person-centred care was felt to be sufficient by 67% of staff, and about one half of staff said training in involving people with dementia and their carers in decisions on care and treatment was sufficient.

4.1.6 Current indicators

None identified.

¹⁹ SCIE (2010) [At a glance 33: Personalisation briefing: Personalisation and mental capacity](#)

²⁰ 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.](#)

²¹ Royal College of Psychiatrists (2011) [Report of the National Audit of Dementia Care in General Hospitals](#)

5 Personalised care - Assessments incorporating shared decision making, recognising the person as an individual and acknowledging the changing nature of the condition

5.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	NICE CG42 1.1.1.5 SCIE Guide 15 SCIE Report 20 Please see page 6 of the prioritisation paper
Proposed quality statement	People with dementia are supported in shared decision making and have their preferences reflected in their care plans.
Draft quality measure	Structure: Evidence of local arrangements to ensure shared decision making is standard practice and care plans reflect individual preferences. Outcome: Evidence that people with dementia feel supported in shared decision making and that their care plan reflects what is important to them.

5.1.2 Effectiveness evidence

SCIE Guide 15 emphasises that health and social care recipients value having information to make choices and decisions for themselves, and that feeling confident and maintaining control is important. Choice and control are key defining aspects of dignity. Withdrawal of respect inhibits choice and control.

SCIE Report 20 explains that personalisation is a central feature of the government policy, ensuring people will receive maximum choice and control over services they receive. Rather than fitting people to services, services should fit the person.

The social model of care as presented in NICE clinical guideline 42 seeks to understand the emotions and behaviours of the person with dementia by placing him or her within the context of his or her social circumstances and biography. By learning about each person with dementia as an individual, with his or her own history and background, care and support can be designed to be more appropriate to individual needs. If, for example, it is known that a man with dementia was once a prisoner of war, it can be understood why he becomes very distressed when admitted to a locked ward. If care providers have learned that a person with dementia has a strong dislike for a certain food, it can be understood why the person might spit it out.

5.1.3 User experience of services

The Alzheimer's Society report 'My name is not Dementia'²², identified ten quality of life indicators as described by people with dementia. These include:

- Sense of personal identity (how the person would describe themselves, their expectations and hopes).
- Independence (practical issues such as being able to look after oneself and exercise choice as well as the feeling of being independent).

Desired outcomes for people with dementia were described in the National Dementia Declaration²³. These included:

- I have control over my life and support to do the things that matter to me.
- Care home staff understand a lot about me and my disability and know what helps me cope and enjoy the best quality of life every day.
- I can access a wide range of options and opportunities for support that suits me and my needs.
- I know how to get this support and I am confident it will help me.

The Alzheimer's Society report Dementia 2012²⁴, found that in a survey of people with dementia living at home:

- 44% of respondents said that professionals either only sometimes (28%) or do not (16%) involve them in decisions about their care and support. In addition, 46% of respondents said either that they only sometimes (25%) or never (21%) have a choice over the support or services they receive.

5.1.4 Safety/safeguarding

SCIE 'at a glance 33'²⁵ emphasises the requirement in the Mental Capacity Act that a person should make their own decisions and where this is not possible because they lack the mental capacity to do so, that they should play a big a role as possible in decision-making processes that directly affect them. It must be assumed that a person has capacity to make a specific decision unless it is demonstrated that they are unable to do so

²² Alzheimer's Society (2010) [My name is not dementia: people with dementia discuss quality of life indicators](#)

²³ Dementia Action Alliance (2010) [National dementia declaration](#)

²⁴ Alzheimer's Society (2012) [Dementia 2012: a national challenge](#)

²⁵ SCIE (2010) [At a glance 33: Personalisation briefing: Personalisation and mental capacity](#)

5.1.5 Current practice

Markers of appropriate training are contained within the Department of Health's 'Common core principles for supporting people with dementia'²⁶:

- Principle 4 Promote independence and encourage activity.

The National Audit of Dementia²⁷ reports that training in person-centred care was felt to be sufficient by 67% of staff, and about one half of staff said training in involving people with dementia and their carers in decisions on care and treatment was sufficient.

5.1.6 Current indicators

None identified.

²⁶ 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.](#)

²⁷ Royal College of Psychiatrists (2011) [Report of the National Audit of Dementia Care in General Hospitals](#)

6 Personalised care - Outcomes of assessments and implementation of the support outlined in care plans

6.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	NICE CG42 1.1.8.1 SCIE Guide 15 SCIE Report 20 Please see page 7 of prioritisation paper
Proposed quality statement	People with dementia receive personalised support outlined in their care plan, including the option to use a personal budget or direct payment with appropriate information and support.
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure that people with dementia receive personalised support outlined in their care plan, including the option to use a personal budget or direct payment with appropriate information and support.</p> <p>Process: Proportion of people receiving a personal budget, including the direct payment option.</p> <p>Numerator – the number of people in the denominator receiving a personal budget, including the direct payment option.</p> <p>Denominator – the number of people with dementia.</p> <p>Outcome: Evidence that people with dementia feel the support they receive is what best suits them, including help with possibly using a personal budget or direct payment.</p>

6.1.2 Effectiveness evidence

NICE clinical guideline 42 recommendation 1.1.8.1 is based on the current legal framework.

SCIE Guide 15 states that direct payments and personal budgets can offer increased independence, choice and control for people using social care services. It is important that people have the support they need to cope with the administrative and human resource management aspects of the schemes.

SCIE Report 20 explains that self-directed support involves finding out what is important to people with social care needs and their families and friends, and helping them to plan how to use the available money to achieve these aims. It is about focusing on outcomes and ensuring that people have choice and control over their support arrangements.

6.1.3 User experience of services

The Alzheimer's Society 'Getting Personal'²⁸ reported that people using direct payments were more satisfied with particular aspects of their care and services than those not using direct payments. In particular they were:

- more likely to say they have received enough information; that the person with dementia is getting all the support they need; and that services made life easier
- more satisfied with support received at an early stage and that services were focused on meeting the person's specific needs
- more satisfied with particular services: help with household tasks (such as cleaning, gardening, shopping); care workers who visit (to help with personal care or provide support in the home during the day or night) and visits from care managers, social workers and occupational therapists.

However, problems were experienced in terms of acquiring and using a direct payment. For example, the process was seen as stressful and there was a lack of information. In addition, there was no indication that survey respondents had found services more flexible.

The survey asked respondents why they did not take up the offer of a direct payment. The top four reasons people gave were:

- 31%: hard enough to cope as it is
- 14%: not confident managing direct payments
- 13%: happy/satisfied with present arrangement
- 11%: too complicated/difficult.

Those who had not been offered a direct payment were asked what they felt might be the potential risks and benefits. The top five views were:

- 17%: able to choose own services
- 14%: open to abuse
- 14%: do not understand money matters
- 13%: don't know what it is
- 11%: adds to responsibilities of carers/more stress/workload.

Desired outcomes for people with dementia were described in the National Dementia Declaration²⁹. These included:

- I can choose what support suits me best, so that I don't feel a burden.

²⁸ Alzheimer's Society (2011) [Getting Personal? Making personal budgets work for people](#)

²⁹ Dementia Action Alliance (2010) [National dementia declaration](#)

SCIE 'at a glance 33'³⁰ points out that carers play a central role in enabling many older people to take up and manage a personal budget. Resource allocation should be worked out on the basis of no carer input and adjusted depending on how much support the carer can provide.

6.1.4 Safety/safeguarding

SCIE 'at a glance 33' emphasises that a person who lacks mental capacity to manage a direct payment may still receive one if a 'suitable' person is available to manage it for them. This is also an option for managed personal budgets.

SCIE 'at a glance 31'³¹ states that providing real choice and control for people who use social care means enabling people to take the risks they choose, particularly in the use of self-directed support and personal budgets. With the support of frontline staff, people using services should be enabled to define their own risks and to recognise, identify and report abuse, neglect and safeguarding issues. Informed choice is vital.

The Mental Health Foundation³² reported some of the difficulties to people with dementia may experience:

- Difficulties in understanding new or complex concepts: the ways in which social care and support is assessed and provided can be difficult for anyone to understand and especially so for a person whose cognitive functions are compromised through dementia
- Having insight into – and conveying – one's own needs. A person might have difficulties with recall, remembering and articulating their needs
- Problem solving to work out the solutions to meet those needs
- Even though the person might not be able to retain information, they might, in a period of insight, be able to come up with a solution that feels good for them
- If a person is unable to express themselves in straightforward language then they are likely to express themselves in verbal and non-verbal behaviour so an assessor should have the skills to observe and understand behaviours.

The Mental Health Foundation notes that In the context of the challenges to communication listed above, it is unlikely that a 'nothing different' approach meets standards of equity and fairness. One size does not fit all.

³⁰ SCIE (2010) [At a glance 33: Personalisation briefing: Personalisation and mental capacity](#)

³¹ SCIE (2010) [At a glance 31: Enabling risk, ensuring safety: Self-directed support and personal budgets](#)

³² Mental Health Foundation (2011) [Personal budgets for people with dementia](#)

6.1.5 Current practice

The Alzheimer's Society 'Getting Personal' reported that:

- 23% of eligible respondents were using a personal budget or direct payment arrangement.
- A further 15% (130 out of 878) said they had been offered a direct payment or personal budget but had declined.
- 60% (855) of the total number of respondents to the survey reported they had not been offered a personal budget. This includes people who would not have been eligible for publicly funded social care.
- People who lived alone appeared to be less likely to be offered, or use, direct payments or personal budgets than those who lived with a carer.
- Younger people with dementia and their carers appeared more likely to have been offered, and be using, direct payments or personal budgets than older people with dementia.
- Direct payments are used particularly to purchase care staff in the home (27%), personal care (22%) and respite services (sitting service 14%; respite care 21%), but also for support such as cleaning and gardening, and for holidays.

6.1.6 Current indicators

National Indicator 130 (VSC17) – Social care clients receiving self directed support (direct payments and individual budgets)³³.

The 2012/13 Social Care Outcomes Framework³⁴ indicator 1C: Proportion of people using social care who receive self-directed support, and those receiving direct payments.

No indicators specific to people with dementia were identified. The Alzheimer's Society 'Getting Personal' (2011) reported that "there is a lack of robust data at a national and local level on access to direct payments or personal budgets for people with dementia. This presents a real challenge to opening up the system to this group. Accurate data is vital and must include overall numbers, as well as drilling down into exactly who is accessing the system and which personal budget options are being used".

³³ Data available from the [National Adult Social Care Intelligence Service](#) (NASIS)

³⁴ Department of Health (2012) [Social Care Outcomes Framework 2012/13](#)

7 Personalised care - Flexibility in the frequency and content of assessments to account for changes in needs, behaviour and personal circumstances

7.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	NICE CG42 1.7.3.1 and 1.10.2.1 Please see page 8 of the prioritisation paper
Proposed quality statement	People with dementia have their care plans [regularly] monitored and reviewed to assess for changes in needs, behaviour and personal circumstances.
Draft quality measure	<p>Structure: Evidence of local arrangements to provide triggers for the monitoring and review of care plans in response to changes in needs, behaviour and personal circumstances.</p> <p>Process: Proportion of people with dementia who have had their care plan reviewed at least [12 months] from the previous care plan review.</p> <p>Numerator – the number of people in the denominator who have had their care plan reviewed at least [12 months] from the previous care plan review.</p> <p>Denominator – the number of people with dementia.</p> <p>Outcome: Evidence that people with dementia and their carers feel care is adapted to accommodate changes in needs, behaviour and personal circumstances.</p>

7.1.2 Effectiveness evidence

NICE clinical guideline 42 recommendation 1.7.3.1 is adapted from the NICE guideline on schizophrenia. The developers also examined quantitative evidence that care management is beneficial both to people with dementia and their carers in identifying an individual's needs, promoting access to services and coordinating the delivery of health and social services. Recommendation 1.10.2.1 states clinicians should be aware of the possibility of pain people in the mild to moderate stages of dementia, and routinely enquire about it. Research that takes into account the underlying physiology of pain suggests that observational scales should be used, whatever the cognitive status of the person.

7.1.3 User experience of services

SCIE 'at a glance 40'³⁵ is a summary of older people's and carers' experiences of using self-directed support and personal budgets. One key

³⁵ SCIE (2010) [At a glance 40: Personal budgets briefing: Learning from the experiences of older people and their carers](#)

message is that older people need to have flexible support plans that can change if their circumstances change. Assumptions should not be made about what care and support older people need and want.

Desired outcomes for people with dementia were described in the National Dementia Declaration³⁶. These included:

- If I develop behaviour that challenges others, people will take time to understand why I am acting this way and help me try to avoid it.

7.1.4 Safety/safeguarding

SCIE 'at a glance 33'³⁷ states that if a person lacks capacity to make some decisions about their support, the local authority are likely to need to put in place more frequent monitoring arrangements than for other people who use services. This applies whether or not they have a personal budget. Attention needs to be given to ensuring the person has as much opportunity as possible to control and review the support they receive. This could include access to:

- information provided in a way that reflects the person's needs
- communication specialists and aids
- advocates including independent mental capacity advocates (IMCAs) for those people who don't have family who can represent them.

7.1.5 Current practice

Markers of appropriate training are contained within the Department of Health's 'Common core principles for supporting people with dementia'³⁸:

- Principle 5 Recognise the signs of distress resulting from confusion and respond by diffusing a person's anxiety and supporting their understanding of the events they experience.

7.1.6 Current indicators

Quality and Outcomes Framework indicator³⁹ 'Dementia 2': Percentage of patients diagnosed with dementia whose care has been reviewed in the preceding 15 months.

2010/11	79.2%
2009/10	79.3%
2008/09	78.9%

³⁶ Dementia Action Alliance (2010) [National dementia declaration](#)

³⁷ SCIE (2010) [At a glance 33: Personalisation briefing: Personalisation and mental capacity](#)

³⁸ 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](#).

³⁹ NHS Information Centre for Health and Social Care (2012) [Quality and Outcomes Framework](#)

8 Personalised care - Sustaining the capabilities and opportunities for people with dementia to self-manage

8.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	NICE CG42 1.5.1.1 SCIE Guide 15 SCIE Report 20 Please see page 9 of the prioritisation paper
Proposed quality statement	People with dementia are supported in their daily living activities and meaningful occupation.
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure that care plans address activities of daily living and meaningful occupation.</p> <p>Process: Proportion of people with dementia supported in daily living activities and meaningful occupation.</p> <p>Numerator – the number of people in the denominator supported in daily living activities and meaningful occupation.</p> <p>Denominator – the number of people with dementia.</p> <p>Outcome: Evidence that people with dementia feel supported in their daily living activities and meaningful occupation.</p>
Definitions	<p>NICE CG42 recommendation 1.5.1.1 states that care plans should always include:</p> <ul style="list-style-type: none"> • consistent and stable staffing • retaining a familiar environment • minimising relocations • flexibility to accommodate fluctuating abilities • assessment and care-planning advice regarding ADLs, and ADL skill training from an occupational therapist • assessment and care-planning advice about independent toileting skills; if incontinence occurs all possible causes should be assessed and relevant treatments tried before concluding that it is permanent • environmental modifications to aid independent functioning, including assistive technology, with advice from an occupational therapist and/or clinical psychologist • physical exercise, with assessment and advice from a physiotherapist when needed • support for people to go at their own pace and participate in activities they enjoy.

8.1.2 Effectiveness evidence

The evidence for clinical guideline 42 recommendation 1.5.1.1 explains that as function deteriorates, it is not uncommon for people with dementia to withdraw from more complex activity and social environments and for others to want to perform tasks for them. However, the literature suggests that functioning in activities of daily living often deteriorates below what would be expected by the illness alone. Therefore the person with dementia, care providers, family and friends should consider opportunities to maintain an active life and social roles and to promote independence beginning in the early stages of the condition. Qualitative evidence on the experience of people with dementia and carers, points to the contribution assistive technology can make by reducing risks and promoting independence.

SCIE Guide 15 emphasises that practical assistance enabling people to live in their own home improves quality of life as well as making economic sense. The absence of such 'low level' support can restrict independence and undermine dignity. For people residing in residential care practical assistance to support the highest possible levels of independence can also support dignity.

SCIE Guide 15 explains that choice and control is about freedom to act, for example to be independent and mobile, as well as freedom to decide. Having choice and control over one's life and involvement - in day-to-day living and the wider community - supports autonomy and self-esteem. For example, being given support to cook a meal will help the person to remain in control and be far more rewarding and meaningful than passively waiting for staff to cook the meal. In terms of involvement in the wider community, being supported to continue with routine daily tasks such as shopping, walking a dog or going to a place of worship, as well as involvement in community activities such as social clubs, can be instrumental in maintaining a person's autonomy.

SCIE Report 20 emphasises that independent living does not mean living on your own or doing things alone, but rather it means 'having choice and control over the assistance and/or equipment needed to go about your daily life. It also emphasises the Department of Health's stance that making choices about how people live their lives is not restricted to those who live in their own home.

8.1.3 User experience of services

The Alzheimer's Society report 'My name is not Dementia'⁴⁰, identified ten quality of life indicators as described by people with dementia. These included:

- Independence (practical issues such as being able to look after oneself and exercise choice as well as the feeling of being independent).

Desired outcomes for people with dementia were described in the National Dementia Declaration⁴¹. These included:

- I have control over my life and support to do the things that matter to me.
- There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible.
- It is easy for me to continue to live in my own home and I and my carer will both have the support needed for me to do this.

The Alzheimer's Society report Dementia 2012⁴², found that in a survey of people with dementia living at home:

- 14% of respondents felt that they were not able to make choices about their day to day life and 37% of respondents felt that they were only sometimes able to make these choices
- 34% of people with dementia responding to the survey said that the support services that they receive only sometimes (25%) or do not (9%) help them to live as independently as they need to.

8.1.4 Safety/safeguarding

No specific safety or safeguarding issues identified.

8.1.5 Current practice

Markers of appropriate training are contained within the Department of Health's 'Common core principles for supporting people with dementia'⁴³:

- Principle 4 Promote independence and encourage activity.

Contained within the National Dementia Strategy⁴⁴:

- Objective 6 Improved community personal support services.

⁴⁰ Alzheimer's Society (2010) [My name is not dementia: people with dementia discuss quality of life indicators](#)

⁴¹ Dementia Action Alliance (2010) [National dementia declaration](#)

⁴² Alzheimer's Society (2012) [Dementia 2012: a national challenge](#)

⁴³ 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](#).

⁴⁴ Department of Health (2009) [National Dementia Strategy](#)

In investigating where the National Dementia Strategy funding had been spent, the All-Party Parliamentary Group⁴⁵ found two thirds of PCTs questioned had not allocated funding or failed to provide evidence of doing so. Of those that did allocate, a wide range of personal support services were outlined, suggesting they have a range of means to support people with dementia living in their own homes.

The National Audit of Dementia⁴⁶ reports that 84% of hospital assessment guidelines/procedures included assessment of functioning (this includes basic activities of daily living, instrumental activities of daily living, activity/ exercise status, gait and balance). However, only 26% of casenotes showed that an assessment of functioning had been carried out for people with dementia admitted to hospital. .

8.1.6 Current indicators

The 2012/13 Social Care Outcomes Framework⁴⁷ indicator 1B: The proportion of people who use services who have control over their daily life.

The 2012/13 NHS Outcomes Framework⁴⁸ indicators:

- 2.1: Proportion of people feeling supported to manage their condition
- 2.2: Employment of people with long-term conditions

⁴⁵ All-Party Parliamentary Group on Dementia (2010) [A missed opportunity?: inquiry into the funding of the National Dementia Strategy](#)

⁴⁶ Royal College of Psychiatrists (2011) [Report of the National Audit of Dementia Care in General Hospitals](#)

⁴⁷ Department of Health (2012) [Social Care Outcomes Framework 2012/13](#)

⁴⁸ Department of Health (2012) [NHS Outcomes Framework 2012/13](#)

9 Personalised care - Opportunities to engage and actively participate in meaningful activities and be involved in the community + Care offered within the context of a range of relationships and communities

9.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	SCIE Guide 15 NICE CG42 1.5.1.1 Please see page 10 and 11 of the prioritisation paper
Proposed quality statement	People with dementia receive support within the context of a range of relationships and opportunities to participate in the wider community, including arrangements for positive risk taking.
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure that people with dementia receive support within the context of a range of relationships and opportunities to participate in the wider community, including arrangements for positive risk taking.</p> <p>Process: Proportion of people with dementia [regularly] participating in activities in the wider community.</p> <p>Numerator – the number of people in the denominator who are regularly participating in activities in the wider community.</p> <p>Denominator – the number of people with dementia.</p> <p>Outcome: Evidence that people with dementia feel their support takes account of a range of relationships and provides opportunities to participate in the wider community.</p>

9.1.2 Effectiveness evidence

The evidence for clinical guideline 42 recommendation 1.5.1.1 explains that as function deteriorates, it is not uncommon for people with dementia to withdraw from more complex activity and social environments and for others to want to perform tasks for them. Social networks, voluntary services, communities, and health and social services can play an important role in socially including people and maximising independence at all stages of illness.

In promoting social inclusion, SCIE Guide 15 prioritised the following key points:

- Good relationships with family and friends, having a role, feeling useful, and being treated with respect are all important to older people.
- Older people who live alone are particularly vulnerable to social isolation and loneliness.

- Social exclusion can increase the chances of mental illness, particularly depression.
- In a long-term study of home care, help to get out of the house was the most common unmet need.
- Overall, the elderly are more likely to be socially excluded.

9.1.3 User experience of services

The Alzheimer's Society report 'My name is not Dementia'⁴⁹, identified ten quality of life indicators as described by people with dementia. These included:

- Relationships or someone to talk to (family, friendships, and relationships with paid carers)
- Ability or opportunity to engage in activities (being able to help out or be busy with activities)
- Ability to practise faith or religion.

Desired outcomes for people with dementia were described in the National Dementia Declaration⁵⁰. These included:

- There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible.
- I have information and support and I can have fun with a network of others, including people in a similar position to me.
- I am making a contribution which makes me feel valued and valuable.
- The importance of helping me to sustain relationships with others is well recognised.
- I feel safe and supported in my home and in my community, which includes shops and pubs, sporting and cultural opportunities.
- My carer and I continue to have the opportunity to develop new interests and new social networks.

The Alzheimer's Society report Dementia 2012⁵¹, found that in a survey of people with dementia living at home:

- When asked if they lost friends after their diagnosis of dementia 12% of respondents said yes, most of them, 28% said yes, some of them, and 47% said no. 4% of respondents reported that they haven't told their friends.

⁴⁹ Alzheimer's Society (2010) [My name is not dementia: people with dementia discuss quality of life indicators](#)

⁵⁰ Dementia Action Alliance (2010) [National dementia declaration](#)

⁵¹ Alzheimer's Society (2012) [Dementia 2012: a national challenge](#)

- 49% of people with dementia responding to the survey said that they sometimes have opportunities to meet and talk to other people with dementia and 18% reported that they never have opportunities (67% in total).
- 22% of respondents to the survey of people with dementia said that they did not feel part of their community and 38% said that they felt part of their community only sometimes.
- 61% of respondents think that their community doesn't understand at all (25%) or has only a little understanding (36%) of how to help them live well. 71% would like their community to understand how to help them live well a lot (57%) or a little (14%) and 67% think that this understanding would make their life a lot (45%) or a little (22%) better.

9.1.4 Safety/safeguarding

SCIE 'at a glance 33'⁵² states that if a person lacks capacity to make some decisions about their support, the local authority/Northern Ireland health and social care trust are likely to need to put in place more frequent monitoring arrangements than for other people who use services (Department of Health, 2010).

9.1.5 Current practice

Markers of appropriate training are contained within the Department of Health's 'Common core principles for supporting people with dementia'⁵³:

- Principle 6 Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice.

9.1.6 Current indicators

None identified.

⁵² SCIE (2010) [At a glance 33: Personalisation briefing: Personalisation and mental capacity](#)

⁵³ 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](#).

10 Delivery of care - Assessment and care of mental and physical health and wellbeing

10.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	NICE CG42 1.1.1.4 and 1.8.1.1 SCIE Guide 15 Please see page 12 of the prioritisation paper
Proposed quality statement	People with dementia [regularly] have their physical and mental health and wellbeing assessed in all care settings.
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure that people with dementia [regularly] have their physical and mental health and wellbeing assessed in all care settings.</p> <p>Process: Proportion of people with dementia who [regularly] have their physical and mental health and wellbeing assessed in all care settings.</p> <p>Numerator – the number of people in the denominator who [regularly] have their physical and mental health and wellbeing assessed.</p> <p>Denominator – the number of people with dementia.</p> <p>Outcome: Evidence that people with dementia and their carers feel general health and well-being is looked after.</p>
Definitions	<p>Physical and mental health and well being includes, but is not limited to:</p> <ul style="list-style-type: none"> • ill health • physical disability • sensory impairment • communication difficulties • nutrition • oral health • foot care • learning disabilities • pain • depression and/or anxiety • hygiene

10.1.2 Effectiveness evidence

The developers of the NICE clinical guideline 42 recognised the complexity in differentiating other physical and mental health conditions in people with dementia. The group highlighted that medical problems and their treatment can be aggravated by the inability of a person with dementia to report his or her own symptoms, so that regular review is essential. This becomes especially important when there has been acute deterioration in either

cognition or behaviour. Common conditions may present in an atypical or non-specific manner. The description of evidence that was used to inform recommendations 1.1.1.4 and 1.8.1.1 referred to a prospective study of 200 elderly outpatients with dementia that identified 248 other medical diagnoses in 124 of them; 92 of the diagnoses were new. The guideline includes several studies that suggest there are higher prevalence rates of certain conditions amongst people with dementia compared to the general population, emphasising the need for pro-active assessment of other physical and mental health issues. For example the presence of dementia was shown to increase the risk of delirium with any concurrent physical illness. For inpatients in a General Hospital, dementia is an independent predictor of poor outcome, including increased mortality, increased length of stay, loss of function and higher rates of institutionalisation which impacts on both the health and social care service providers.

Research used to inform SCIE Guide 15 identified some specific issues concerning the management of pain in people with dementia. Pain was shown to exacerbate the behavioural and psychological symptoms of dementia and could result in challenging behaviour. Use of bank and agency staff can reduce pain recognition because regular staff would know the person and therefore be more likely to identify pain related behavior. Pain was also a cause of people waking at night; and that restlessness should trigger concerns about whether the person is suffering pain.

SCIE Guide 15 also reported evidence that pain in people with cognitive impairment, including learning disabilities and dementia is under diagnosed and under treated.

10.1.3 User experience of services

The Alzheimer's Society report 'My name is not Dementia'⁵⁴, identified ten quality of life indicators as described by people with dementia. These included:

- Physical health (family, friendships, and relationships with paid carers)

Desired outcomes for people with dementia were described in the National Dementia Declaration⁵⁵. These included:

- I feel supported and understood by my GP and get a physical check up regularly without asking for it.

⁵⁴ Alzheimer's Society (2010) [My name is not dementia: people with dementia discuss quality of life indicators](#)

⁵⁵ Dementia Action Alliance (2010) [National dementia declaration](#)

10.1.4 Safety/safeguarding

The National Audit of Dementia⁵⁶ reported that people with dementia have increased risk of pressure sores, and with poor nutritional status, it is important that pressure sore risk assessment is carried out. This did not occur in over 10% of casenotes audited

10.1.5 Current practice

The National Audit of Dementia reviewed current practice in relation to the physical assessment of people with dementia admitted to hospital. The results show that although the general medical assessment of people with dementia seems adequate, the assessment of function did not routinely involve a standardised assessment. 84% of hospitals reported that multidisciplinary assessment includes assessment of functioning using a standardised instrument. However, only 26% of casenotes showed that this was included in the assessment.

The audit looked at pain management and found that 24% of casenotes showed that the patient had not been asked about presence of any pain as part of the assessment.

The audit also reviewed practice relating to psychological assessment. The report stated that hospitals had not yet taken seriously the need to routinely assess mental state as part of a comprehensive assessment of older people:

- 74% of hospitals reported that multidisciplinary assessment includes assessment of mental state.
- 28% of hospitals reported that an assessment of mental state is carried out on all patients over the age of 65 admitted to hospital.
- 25% of hospitals said that their multidisciplinary assessment includes mental state and that this is carried out for all patients over 65.

Given that the focus of this audit was people with a known diagnosis of dementia, it was expected that there would be a relatively high level of mental state assessment. However, only 43% of casenotes showed that a standardised mental status test had been carried out.

Delirium is likely to be misdiagnosed as dementia, missing opportunities for the urgent treatment that is required if its poor outcome is to be avoided. However, in the National Audit, routine screening does not cover delirium which is therefore often likely to be missed. It is likely that prevention strategies are not being used. 33% of hospitals have policies or guidelines in place to ensure that patients with dementia or cognitive impairment are

⁵⁶ Royal College of Psychiatrists (2011) [Report of the National Audit of Dementia Care in General Hospitals](#)

screened for delirium, using a standardised method. Only 9% of casenotes showed that a screen for delirium had been carried out.

Very low use of standardised assessments for the detection of depression was reported, despite its association with many long term conditions, its independent association with poor prognosis and its treatability. 2% of casenotes stated that a standard mood (depression) test had been carried out.

A GP survey by the National Audit Office⁵⁷ found that:

- 90% of GPs maintain a register of patient with dementia. Of those GPs, 80% report that the register prompts them to undertake regular patient reviews.
- Components of reviews varied widely. For example, over 50% reported assessment of physical health check whilst just over 10% reported assessing social status / needs.

10.1.6 Current indicators

None identified.

⁵⁷ National Audit Office (2010) [Improving dementia services in England - an interim report](#)

11 Delivery of care – Caring for people with dementia with dignity, respect, kindness and compassion

11.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	NICE CG42 1.1.1.2 SCIE Guide 15 Please see page 13 of the prioritisation paper
Proposed quality statement	People with dementia are treated with dignity, respect, kindness and compassion.
Draft quality measure	Structure: Evidence that local training on dementia awareness includes how to treat people with dementia with dignity, respect, kindness and compassion. Outcome: Evidence that people with dementia feel treated with dignity, respect, kindness and compassion.

11.1.2 Effectiveness evidence

NICE clinical guideline 42 recommendation 1.1.13 is based on consensus of professional opinion.

SCIE Guide 15 described research evidence concerning the basis upon which person centred care should be provided and how best to support someone to retain respect and dignity. The report references that 'consciously reviewing [a persons] previous lives and achievements' was a strategy that helped them to maintain a positive attitude and to 'resist the demoralising effects of their situation'. The report also states that maintaining a sense of identity is key to retaining self-esteem. For people with dementia, reminiscence activity has been used for many years to reaffirm the identity of individuals based on their own personal history. Life story books are also a useful tool for those working with people with cognitive impairments.

SCIE Guide 15 also includes discussion of evidence about enabling people to retain as much autonomy as possible. It focuses on the need for good-quality communication between professionals and people with dementia so that a person with dementia is able to retain and utilise their remaining abilities as much as possible.

11.1.3 User experience of services

The Alzheimer's Society's report 'Counting the Cost'⁵⁸ identified key carer concerns as: care staff not recognising or understanding dementia; a lack of person-centred care; not being helped to eat and drink; a lack of opportunity for social interaction; not as much involvement in decision-making as wished for (for both the person with dementia and carer); and the person with dementia being treated with a lack of dignity and respect.

SCIE Guide 15 highlighted specific concerns in relation to dignity and respect linked to hygiene and personal appearance. An analysis of UK data from the Dignity in Older Europeans study found that the self-respect of older people could be undermined by neglect of patients' appearance and clothing and that, even in death, maintaining a respectable appearance is very important to people.

Desired outcomes for people with dementia were described in the National Dementia Declaration⁵⁹. These included:

- I am treated with dignity and respect whenever I need support from services.

11.1.4 Safety/safeguarding

None identified.

11.1.5 Current practice

The National Audit of Dementia⁶⁰ reported evidence from a review of relevant literature concerning patient experience in accessing services for dementia. The review identified key areas of patient and carer priorities for the care of people with dementia in hospitals. These were summarised as:

- care planning and support, from admission to discharge, which is both person-centred and recognises the particular needs associated with the dementia (rather than the acute condition alone);
- care of patients with acute confusion;
- maintaining dignity in care;
- maintenance of patient ability;
- communication and collaboration between staff and patients/carers;

11.1.6 Current indicators

None identified

⁵⁸ Alzheimer's Society (2009) [Counting the cost](#)

⁵⁹ Dementia Action Alliance (2010) [National dementia declaration](#)

⁶⁰ Royal College of Psychiatrists (2011) [Report of the National Audit of Dementia Care in General Hospitals](#)

12 Delivery of care - Safeguarding of people with dementia including balancing safety with personal liberty, mental capacity and positive risk taking

12.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	NICE CG42 1.4.1.1 and 1.1.6.1 Please see page 14 of the prioritisation paper
Proposed quality statement	Staff supporting people with dementia apply the Mental Capacity Act – Deprivation of Liberty Safeguards and balance safety with personal liberty, mental capacity and positive risk taking.
Draft quality measure	<p>Structure: Evidence of local arrangements to train staff in applying the Mental Capacity Act – Deprivation of Liberty Safeguards and balancing safety with personal liberty, mental capacity and positive risk taking.</p> <p>Process: Proportion of staff supporting people with dementia who are trained in applying the Mental Capacity Act – Deprivation of Liberty Safeguards and balancing safety with personal liberty, mental capacity and positive risk taking.</p> <p>Numerator – the number of staff in the denominator trained in applying the Mental Capacity Act – Deprivation of Liberty Safeguards and balancing safety with personal liberty, mental capacity and positive risk taking.</p> <p>Denominator – the number of staff supporting people with dementia.</p> <p>Outcome: Evidence that people with dementia and their carers feel freedoms are not unduly restricted.</p>

12.1.2 Effectiveness evidence

The recommendations from NICE clinical guideline 42 are primarily based on statutory legal framework and variations in its implementation.

12.1.3 User experience of services

SCIE Guide 3 concerning the assessment of mental health needs in older people highlighted that worry about risk and danger permeates assessment work with older people. The report suggests that relatives, neighbours, the public and involved professionals all experience and react to this worry. The Department of Health's consultation on the Green Paper Independence, well-being and choice suggests that service users believe that professionals are too concerned about risk, and that this gets in the way of enabling service users to do what they want to do. It suggests that the promotion of a person centred approach aims to maximise independence and minimise risk, and

often involves identifying and helping to resolve conflict and disagreement over risk and danger.

12.1.4 Safety/safeguarding

None identified.

12.1.5 Current practice

SCIE Guide 31 'Commissioning and monitoring IMCA services' reports that there continues to be significant local variance regarding the level of instructions for the IMCA service which they report cannot all be attributed to differences in population profiles. For example, in some local authorities, eligible instructions in year three exceeded 40 per 100,000 population (all age) while in others it was below 5. Some IMCA providers report at times difficulties in meeting the demand for the IMCA service, however in other areas IMCA services are working under capacity. This emphasises the local variation in terms of use and access of what is a statutory obligation. Concern was also raised as to whether the discretionary powers to instruct an IMCA are being used effectively. Section 5.23 of the MCA Code of Practice says that all practical means should be used to enable and encourage the person to participate in best interests decisions. The instruction of an IMCA is a practical measure which should be considered in all cases where the discretionary power is available.

12.1.6 Current indicators

Mental Capacity Act Deprivation of Liberty Safeguards (MCA DOLS) collection⁶¹:

The MCA DOLS collection captures information on the number of authorisations accepted and declined by disability, of which dementia is a subset of mental health disability type.

Abuse of Vulnerable Adults (AVA) collection:

Table 1 from the AVA collection captures information on the number of alerts, referrals, repeat referrals and completed referrals, by age, primary client group and gender of the vulnerable adult.

Table 1 includes data on dementia clients as a secondary client type under the Mental Health primary client group.

⁶¹ The Information Centre for Health and Social Care available via www.ic.nhs.uk

13 Organisation of services - Coordination of care between health and social care, including transitions between settings

13.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	NICE CG42 1.1.7.3, 1.2.1.2 and 1.2.1.3 Please see page 15 of the prioritisation paper
Proposed quality statement	People with dementia experience care that is coordinated between health and social care, especially when transferring between services.
Draft quality measure	Structure: Evidence of local arrangements to ensure that health and social care services communicate and coordinate the care of people with dementia. Outcome: Evidence that people with dementia and their carers feel health and social care communicate and coordinate their care.

13.1.2 Effectiveness evidence

A review of the literature to inform NICE clinical guideline 42 found that care management is beneficial both to people with dementia and their carers. It reported that care managers can identify an individual's needs, promote access to services and coordinate the delivery of health and social services, and respond to the developing needs of the person with dementia or his or her carer. Through their on-going relationship with the person with dementia and his or her carer, care managers may be better able to communicate with the person with dementia and enable him or her to exercise the control over services that the qualitative evidence suggests they want. However, because the models of care management that have been investigated vary, the guideline developers felt it was not possible to identify the most effective models or the individual components that contribute to their overall effectiveness. The guideline does reference a UK study of care management for people with dementia that found that care management delivered better outcomes and was more effective at maintaining people with dementia at home than standard community old age mental healthcare. Several other studies conducted in other countries are also referenced that found similar evidence for potentially beneficial effects of care management for people with dementia and their carers. However, the guideline developers recognised that the studies did not establish that the benefits arise specifically from care management, as the schemes studied provide care management along with other interventions.

A systematic review of the evidence on the best way to plan and organise services for people with dementia and their carers was also conducted as part

of the guideline development process. The review found that there were very few studies where a clear comparison between services could be carried out to identify the best way of planning or organising services. The research that was identified was deemed not to be applicable to UK settings due to them being based on different systems for organising and funding health and social care, primarily in Scandinavia and the United States.

13.1.3 User experience of services

The National Audit of Dementia⁶² services reviewed practice in relation to discharge co-ordination. The audit reported evidence that people with dementia often stay in hospital longer than needed and can be inappropriately discharged from hospital. The report emphasised the important role played by discharge co-ordinator in ensuring all aspects of an individual's support needs are assessed and provided in a timely / co-ordinated manner.

Desired outcomes for people with dementia were described in the National Dementia Declaration⁶³. These included:

- I only go into hospital when I need to and when I get there staff understand how I can receive the best treatment so that I can leave as soon as possible.

13.1.4 Safety/safeguarding

None identified.

13.1.5 Current practice

Contained with the National Dementia Strategy⁶⁴:

- Objective 8 Improved quality of care for people with dementia in general hospitals.
- Objective 15 Improved assessment and regulation of health and care services and how systems are working for people with dementia and their carers.

The National Audit of Dementia reviewed how discharge processes were co-ordinated and managed. The audit recognised that the discharge process was complex and that many different professionals plus family carers may be involved with the discharge process and good practice guidance recommends that there is a named person with overall responsibility for discharge co-ordination. The audit includes a casenote audit looking at whether all aspects of support had been covered in the discharge plan. A majority of casenotes audited did contain an up to date discharge plan. However, a lower

⁶² Royal College of Psychiatrists (2011) [Report of the National Audit of Dementia Care in General Hospitals](#)

⁶³ Dementia Action Alliance (2010) [National dementia declaration](#)

⁶⁴ Department of Health (2009) [National Dementia Strategy](#)

percentage of casenotes showed that the plan covered all identified support needs. A copy of the plan had been passed on to patients/carers in a minority of cases:

- 67% of casenotes contained a single plan for discharge which included updated information.
- 58% of casenotes showed evidence that any support needs that had been identified were included in the discharge plan or summary.
- 41% of casenotes stated that the patient and/or carer received a copy of the plan or summary.

The audit asked about a named person in the hospital with overall or lead responsibility for discharge co-ordination for people with dementia (this role could include other responsibilities, e.g. all complex discharges):

- 32% of hospitals have a named person who takes responsibility for discharge co-ordination for people with dementia. Of these hospitals:
- 56% reported that the person with overall responsibility for discharge co-ordination has training in ongoing needs of people with dementia.
- 84% reported that the person with overall responsibility for discharge planning has experience of working with people with dementia and their carers.
- 18% of hospitals have a person with overall responsibility for discharge co-ordination who has had training in ongoing needs of people with dementia and the person has experience of working with people with dementia and their carers.

Less than a quarter of hospital Boards/Trust Executive Boards regularly look at information about delayed discharges of people with dementia and only 8% review re-admissions of people with dementia.

The Alzheimer's Society's report 'Counting the Cost'⁶⁵ states that over a third of people with dementia who go into hospital from living in their own homes are discharged to a care home setting.

Markers of appropriate training are contained within the Department of Health's 'Common core principles for supporting people with dementia'⁶⁶:

- Principle 8 Work as part of a multi-agency team to support the person with dementia.

13.1.6 Current indicators

None identified

⁶⁵ Alzheimer's Society (2009) [Counting the cost](#)

⁶⁶ 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](#).

14 Organisation of services - Strategic planning including training needs of staff and workforce capacity

14.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	NICE CG42 1.1.9.1, 1.1.9.3 and 1.1.9.4 SCIE Guide 15 Please see page 16 of the prioritisation paper
Proposed quality statement	Services supporting people with dementia strategically plan to provide appropriate workforce capacity and access to dementia-care training for staff and unpaid carers.
Draft quality measure	<p>Structure:</p> <p>a) Evidence of local strategic planning to provide appropriate workforce capacity and access to dementia-care training for staff and unpaid carers.</p> <p>b) Evidence of appropriate staffing ratios according to mix of residents and skill mix of staff.</p> <p>Process:</p> <p>a) Proportion of staff supporting people with dementia who have received dementia-care training.</p> <p>Numerator – the number of staff in the denominator who have received dementia-care training.</p> <p>Denominator – the number of staff supporting people with dementia.</p> <p>b) Proportion of unpaid carers of people with dementia who received dementia-care training.</p> <p>Numerator – the number of unpaid carers in the denominator who received dementia-care training.</p> <p>Denominator – the number of unpaid carers of people with dementia.</p> <p>Outcome: Evidence that people with dementia, staff and carers feel staffing levels are appropriate and that dementia-care training is accessible.</p>
Definitions	Appropriate training competencies are detailed by the 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 .

14.1.2 Effectiveness evidence

The developers of NICE clinical guideline 42 primarily focussed their discussion of the evidence in this section on the potential benefits of staff and carers being able to access appropriate dementia-care training rather than

strategic workforce planning. Recommendations 1.1.9.1, 1.1.9.3 and 1.1.9.4 are primarily focused on identifying processes through which training can be more widely available to staff and carers involved in the care of people with dementia.

SCIE guide 15 explores the training of staff to support independence and maintaining dignity. Choice and control are important to support the maintenance of skills, particularly in hospital. Some of the reasons identified by staff for not maintaining dignity in care are: levels of training, staff and other shortages, lack of time and emphasis on performance targets.

14.1.3 User experience of services

None identified.

14.1.4 Safety/safeguarding

None identified.

14.1.5 Current practice

Contained with the National Dementia Strategy⁶⁷:

- Objective 14 A joint commissioning strategy for dementia.

Markers of appropriate training are contained within the Department of Health's 'Common core principles for supporting people with dementia'⁶⁸:

- Principle 7 Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia.

In investigating where the National Dementia Strategy funding had been spent, the All-Party Parliamentary Group⁶⁹ found that 89% of PCTs had strategies of one form or another in place or in development. However, nearly half of PCTs responding made it clear that strategies were still in development, suggesting a significant number have missed the March 2010 deadline for these to be in place.

14.1.6 Current indicators

Prevalence of dementia is collated in Joint Strategic Needs Assessments⁷⁰.

⁶⁷ Department of Health (2009) [National Dementia Strategy](#)

⁶⁸ 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](#).

⁶⁹ All-Party Parliamentary Group on Dementia (2010) [A misspent opportunity?: inquiry into the funding of the National Dementia Strategy](#)

⁷⁰ Data available from the [National Adult Social Care Intelligence Service](#) (NASIS)

15 De-stigmatisation – Changing opinion in the community and in services about people with dementia

15.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	None identified
Proposed quality statement	Services supporting people with dementia work to change opinion in the community and in services about people with dementia and the condition.
Draft quality measure	<p>Structure: Evidence of local work to change opinion in the community and in services about people with dementia and the condition.</p> <p>Outcome: Evidence from that people with dementia and their carers feel services work to change opinion in the community and in services about people with dementia and the condition.</p>

15.1.2 Effectiveness evidence

None identified.

15.1.3 User experience of services

The Alzheimer's Society report Dementia 2012⁷¹, report included findings from a national poll of 2,070 members of the general public which found that respondents perceive people with dementia to have either a fairly bad quality of life in the UK (39%) or a very bad quality of life in the UK (19%). Only 1% thought that people with dementia have a very good quality of life, while 6% thought they had a fairly good quality of life.

A YouGov poll commissioned by the Alzheimer's Society shows that: over two-thirds of people with dementia do not always feel a part of their community; and three-quarters don't feel that society is geared up to deal with people with dementia

The report also described findings from a national survey of people with dementia. When asked if they lost friends after their diagnosis of dementia 12% of respondents said yes, most of them, 28% said yes, some of them, and 47% said no. 4% of respondents reported that they haven't told their friends.

⁷¹ Alzheimer's Society (2012) [Dementia 2012: a national challenge](#)

The Alzheimer's Society report 'My name is not Dementia'⁷², identified ten quality of life indicators as described by people with dementia. These included:

- Experience of stigma (negative experiences of stigma as well as the desire to be treated fairly).

Desired outcomes for people with dementia were described in the National Dementia Declaration⁷³. These included:

- My neighbours, friends, family and GP keep in touch and are pleased to see me.
- Neither I nor my family feel ashamed or discriminated against because I have dementia. People with whom we come into contact are helpful and supportive.

15.1.4 Safety/safeguarding

None identified.

15.1.5 Current practice

Contained with the National Dementia Strategy⁷⁴:

- Objective 1 Improving public and professional awareness and understanding of dementia.

The Alzheimer's Society report 'Dementia 2012'⁷⁵ raises a range of issues and challenges that the whole of society need to address to improve outcomes for people with dementia and their families, friends / carers. The report suggests that the challenge is so extensive that good quality of life for people with dementia and their carers cannot be achieved in isolation or by a few. They argue that a society wide partnership is required. This partnership must have people with dementia and carers at the heart and must include a range of partners from business, the public sector, civic and voluntary organisations, as well as the government, NHS and local authorities.

The top five solutions that people with dementia report could be done in their community to make it easier for them to live life the way they want are:

- better understanding of dementia and less social stigma attached (25%)
- more public awareness of the condition (17%)
- more local activities and opportunities to socialise (13%)

⁷² Alzheimer's Society (2010) [My name is not dementia: people with dementia discuss quality of life indicators](#)

⁷³ Dementia Action Alliance (2010) [National dementia declaration](#)

⁷⁴ Department of Health (2009) [National Dementia Strategy](#)

⁷⁵ Alzheimer's Society (2012) [Dementia 2012: a national challenge](#)

- more tolerance and patience from others (7%)
- more community spirit (7%).

People with dementia would like the following to have more of an understanding of dementia:

- family (54%)
- friends (58%)
- neighbours (51%)
- health and social care professionals (58%)
- people working in banks, post offices and shops (62%)
- the police (54%).

15.1.6 Current indicators

None identified.

16 Organisation of services - Built environments and the effect on people with dementia

16.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	NICE CG42 1.1.10.1, 1.1.11.2 and 1.1.10.3 Please see page 18 of the prioritisation paper
Proposed quality statement	Services purchasing or organising living arrangements or care home placements ensure the social components and design of the built environment meet the needs of people with dementia.
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure that when purchasing or organising living arrangements or care home placements, services consider the social components and design of the built environment.</p> <p>Outcome: Evidence that people with dementia and their carers feel that the social components and design of accommodation are dementia friendly.</p>
Definitions	<p>Specific components of the built environment include, but are not limited to:</p> <ul style="list-style-type: none"> • lighting • colour schemes • floor coverings • assistive technology • signage • garden design • access <p>Social components include but are not limited to:</p> <ul style="list-style-type: none"> • size of units • mix of residents • skill mix of staff

16.1.2 Effectiveness evidence

Recommendations in NICE clinical guideline 42 concerning the principles of the design of care homes and other caring environments for people with dementia are largely based on theory but have some support from empirical research. The aim of design principles is to maximise the abilities of people with dementia while minimising negative features of the environment. When considering environmental design, it is important to be aware that individual requirements will vary both according to the individual's personal history, culture and religion, and the degree of his or her impairment.

Department of Health guidance⁷⁶ sets out minimum standards for the physical environment of residential homes. Good practice regarding the design of environments for people with dementia includes incorporating features that support special orientation and minimise confusion, frustration and anxiety. The guideline developers did highlight that some design features may be better for some individuals with dementia but detrimental to others. For example, good practice guides to care home design recommend both simplified environments and moderate levels of environmental stimulation – environments that offer opportunities for stimulation and exploration may enhance the quality of life of some people with dementia, but others may find such environments over stimulating, disorienting and confusing.

16.1.3 User experience of services

There is research evidence included in NICE clinical guideline 42 indicating that smaller units accommodating fewer residents are beneficial to people with dementia. Studies indicate that larger units are associated with worse outcomes for residents with dementia in terms of agitation, intellectual deterioration, emotional disturbance, territorial conflicts, space invasion and aggressiveness towards other residents. By contrast, smaller units are associated with gains that include less anxiety and depression, greater mobility, increased supervision and interaction between staff and residents, increased social interaction between residents, higher motor functioning, improved or maintained activities of daily living (ADLs) and less use of antibiotic and psychotropic. Research comparing people living in traditional nursing homes and hospitals with residents in non-institutional settings was also referenced. The findings suggested that people in non-institutional settings are less aggressive, preserve better motor functions, require lower usage of tranquilising drugs and have less anxiety. Relatives also report greater satisfaction and less burden associated with non-institutional facilities, and staff also prefer less institutional environments. However, it was also noted that the impact the environment can have is highly dependent on the way in which care is provided. The guideline references a ethnographic study that found the therapeutic potential of the home-like environment was undermined by inflexible and formal ‘institutional’ care-giving practices.

The Alzheimer’s Society report ‘My name is not Dementia’⁷⁷, identified ten quality of life indicators as described by people with dementia. These included:

- Environment (physical aspects of the environment such as it being safe and secure as well as more ambient aspects such as peace and quiet)

⁷⁶ Department of Health (2003) [National Minimum Standards: Care Homes for Older People](#)

⁷⁷ Alzheimer's Society (2010) [My name is not dementia: people with dementia discuss quality of life indicators](#)

Desired outcomes for people with dementia were described in the National Dementia Declaration⁷⁸. These included:

- I know that with a diagnosis of dementia comes support to live well through assistive technologies as well as more traditional treatment types.

16.1.4 Safety/safeguarding

None identified.

16.1.5 Current practice

Contained with the National Dementia Strategy⁷⁹:

- Objective 10 Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers.

The National Audit of Dementia⁸⁰ included a number of indicators that focused on the physical ward environment in hospitals. They included some evidence from observations of care which showed that in some wards, lack of familiar items, excess noise levels, a lack of orientation cues and not having items such as buzzers or drinks in reach negatively affected people with spatial and perceptual problems. There was also much scope to improve activities and resources to provide stimulation for people with dementia, with this being identified as an area for action in 55 out of 105 wards.

16.1.6 Current indicators

None identified

⁷⁸ Dementia Action Alliance (2010) [National dementia declaration](#)

⁷⁹ Department of Health (2009) [National Dementia Strategy](#)

⁸⁰ Royal College of Psychiatrists (2011) [Report of the National Audit of Dementia Care in General Hospitals](#)

17 Organisation of services – Opportunities for involvement in service planning, service improvement and relevant high quality research

17.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	SCIE Guide 15 NICE CG42 1.2.1.2 Please see page 19 of the prioritisation paper
Proposed quality statement	People with dementia have opportunities to be involved in service planning, service improvements and high quality research
Draft quality measure	Structure: Evidence of local arrangements to ensure people with dementia have opportunities to be involved in service planning, service improvements and high quality research Outcome: Evidence that people with dementia feel involved in service planning, service improvements and high quality research

17.1.2 Effectiveness evidence

The recommendations concerning people with dementia being given opportunities to be involved in service planning and service improvements are based on the consensus expert opinion of the Guideline Development Group. The reference to the need for participation in high quality research highlights the need for an increase in the amount of well designed research in this area.

Within the SCIE Guide 15 reference is made to evidence showing how enabling people to have choice and control over what happens to them is important in supporting the maintenance of skills, particularly in hospital.

17.1.3 User experience of services

SCIE Guide 17⁸¹ suggests that although there is a considerable amount of research highlighting that only a very small minority of people with dementia cannot express their views, people with dementia are seriously under represented in the majority of systems for participation. There is a lack of systems to support participatory practice so that care managers and social workers are often asked to make life changing decisions on behalf of a person with dementia, such as deciding whether or not to recommend a move into a care home, without having had time to build up a personal relationship with him or her. The report also raises some issues concerning participation methods and that people based within the community who are not able to

⁸¹ SCIE (2007) [Guide 17 Participation of service users in developing social care](#)

travel easily can be excluded from opportunities to participate where the primary method is through face to face meetings.

Desired outcomes for people with dementia were described in the National Dementia Declaration⁸². These included:

- I regularly read and hear about new developments in research.
- I am confident that there is an increasing investment in dementia research in the UK. I understand the growing evidence about prevention and risk reduction of dementia.
- As a person living with dementia, I am asked if I want to take part in suitable clinical trials or participate in research in other ways.
- I believe that research is key to improving the care I'm receiving now.
- I believe that more research will mean that my children and I can look forward to a range of treatments when I need it and there will be more treatments available for their generation.

The Alzheimer's Society report Dementia 2012⁸³, found that in a survey of people with dementia living at home:

- 83% of respondents said that research into improving care for people now was important; 83% said that research into the cause was important and 87% said that research into the cure was important. 82% of respondents also felt that there should be more funding for dementia research.
- 75% of respondents thought that it was either very or quite important to hear about research into dementia and 64% indicated that being asked to take part in dementia research was important for them.

17.1.4 Safety/safeguarding

None identified

17.1.5 Current practice

Contained with the National Dementia Strategy⁸⁴:

- Objective 5 Development of structured peer support and learning networks.
- Objective 16 A clear picture of research evidence and needs.

SCIE Guide 17(2007) concerning the participation of adult service users, including older people, in developing social care refers to the need for a whole system approach to participation and involvement of service users. The reports states that whole systems approaches are a useful way of looking at participation because:

⁸² Dementia Action Alliance (2010) [National dementia declaration](#)
⁸³ Alzheimer's Society (2012) [Dementia 2012: a national challenge](#)
⁸⁴ Department of Health (2009) [National Dementia Strategy](#)

- Organisations must change at every level, from senior management to front line staff, if they want to achieve meaningful participation.
- Participation should become part of daily practice, not a one-off activity.
- Participation operates at different levels. There are many ways to involve service users in different types of decisions.

SCIE Guide 17 provides a number of working examples of where people are being involved and participating in the delivery and development of services. However these are good practice examples. There is significant variation in how different service providers include and work with service users to plan and deliver services. As previously mentioned, it is also widely recognised that there is a need for further well designed research in the general area of care provision for dementia.

SCIE Report 20 discusses the proposed benefits of “co-production” of services where service users have an equal role in the planning and delivery of services. It states that service users should be regarded as an asset encouraged to work alongside professionals as partners in the delivery of services’.

17.1.6 Current indicators

None identified

18 Organisation of services – Access to independent and specialist advocacy organisations and formal independent mental capacity advocate (IMCA) services

18.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	SCIE Guides 31, 32, 39 and 41 NICE CG42 1.1.4.2 SCIE Guide 15 Please see page 20 of the prioritisation paper
Proposed quality statement	People with dementia and their carers are supported to access formal independent mental capacity advocate services and advocacy organisations.
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure that people with dementia and their carers are supported to access formal independent mental capacity advocate services and advocacy organisations.</p> <p>Process: Proportion of people with dementia, and their carers, accessing formal independent mental capacity advocate services or advocacy organisations.</p> <p>Numerator – the number of people in the denominator accessing formal independent mental capacity advocate services or advocacy organisations.</p> <p>Denominator – the number of people with dementia and their carers.</p> <p>Outcome: Evidence that people with dementia feel supported to access formal independent mental capacity advocate services and advocacy organisations</p>

18.1.2 Effectiveness evidence

Recommendations contained in NICE clinical guideline 42 concerning access to formal advocacy services are based on the guideline development group members consensus opinion and statutory legislation.

Recommendations contained in SCIE Guides 31, 32, 39 and 41 are based on the statutory legal framework set out in the Mental Capacity Act 2005⁸⁵. These guides provide support in commissioning and implementing the provision of formal independent mental capacity advocates.

SCIE guide 15 refers to a study by the Older People’s Advocacy Alliance (OPAAL) UK: The study found that:

⁸⁵ [Mental Capacity Act \(England & Wales\) 2005](#)

- older people thought awareness should be raised about advocacy
- advocacy had been used for a number of reasons: protection from abuse; combating discrimination; obtaining and changing services; securing and exercising rights; being involved in decision-making and being heard
- participants identified two sets of successful outcomes - those relating to tangible or material gains (for example, obtaining a service) and those bound up in feelings of greater confidence and self-esteem and of being better equipped to deal with life situations themselves.

18.1.3 User experience of services

None identified.

18.1.4 Safety/safeguarding

None identified.

18.1.5 Current practice

SCIE Guide 31 'Commissioning and monitoring IMCA services' reports that there continues to be significant local variance regarding the level of instructions for the IMCA service which they report cannot all be attributed to differences in population profiles. For example, in some local authorities, eligible instructions in year three exceeded 40 per 100,000 population (all age) while in others it was below 5. Some IMCA providers report at times difficulties in meeting the demand for the IMCA service, however in other areas IMCA services are working under capacity. This emphasises the local variation in terms of use and access of what is a statutory obligation. Concern was also raised as to whether the discretionary powers to instruct an IMCA are being used effectively. Section 5.23 of the MCA Code of Practice says that all practical means should be used to enable and encourage the person to participate in best interests decisions. The instruction of an IMCA is a practical measure which should be considered in all cases where the discretionary power is available.

The National Audit of Dementia⁸⁶ reported that health and social care professionals should be able to provide information to patients with dementia and their carers about advocacy, and its use should be encouraged. 83% of hospitals had access to advocacy services with experience and training in working with people with dementia.

18.1.6 Current indicators

None identified.

⁸⁶ Royal College of Psychiatrists (2011) [Report of the National Audit of Dementia Care in General Hospitals](#)

19 Support for unpaid carers - Proactive approaches to adapt support given to carers according to changes in the carer's preferences, needs and the condition of the person with dementia + Differences between the views of people with dementia and their unpaid carers

19.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	NICE CG42 1.11.1.1, 1.11.2.1 and 1.11.2.2 SCIE Guide 9 Please see page 21 of the prioritisation paper
Proposed quality statement	Carers of people with dementia have their needs [formally] assessed and are provided with support that adapts to changes in their preferences, needs and the condition of the person with dementia.
Draft quality measure	<p>Structure: Evidence of local arrangements to provide statutory carers assessments and adapt support to changes in carer preferences, needs and the condition of the person with dementia.</p> <p>Process: Proportion of carers of people with dementia who have a carers assessment.</p> <p>Numerator – the number of carers in the denominator who have a carers assessment.</p> <p>Denominator – the number of carers of dementia.</p> <p>Outcome: Evidence from carers that they received an assessment and feel support adapts to changes in their preferences, needs and the condition of the person with dementia.</p>
Definitions	<p>A carers assessment is a statutory right as set out in the Carers Act 2004.</p> <p>Assessments and support should accommodate for differences between the views of unpaid carers and people with dementia.</p>

19.1.2 Effectiveness evidence

The developers of NICE clinical guideline 42 considered the extensive literature on interventions with family carers of people with dementia. Interventions involving training or stress management or involving the person with dementia alongside the carer appeared to have the largest effect on the carer's psychological health and well-being. It is clear that carer interventions can be effective in relation to psychological health, burden and well-being, although the relatively small effect sizes for some domains and the large variability between studies suggest that there is much to be learned regarding which interventions will be most helpful for which carers.

The qualitative review identified evidence that carers benefit from and/or value educational/information-giving interventions, support groups and helplines, all of which can be provided by voluntary sector organisations. However, evidence suggests that providers of educational interventions for carers of people with dementia at an early stage after diagnosis should be aware of the possibility that education about dementia may sometimes have an adverse effect on a carer's anxiety.

SCIE guide 9 provides practice points based on the current legal framework.

19.1.3 User experience of services

“Personalised support both for carers and those they support, enabling them to have a family and community life” is priority area 3 in the Next Steps for the Carers Strategy⁸⁷. The consultation on the national carers strategy found that the time from referral to receipt of assessment should be shorter: “*The system is completely oblivious to the impact the slow referral and assessment systems have on the lives of those it is set up to help and their carers*” (quote from a carer).

Desired outcomes for people with dementia were described in the National Dementia Declaration⁸⁸. These included:

- My carer can access respite care if and when they want it, along with other services that can help support them in their role.
- My carer also has their own support network that suits their own needs.
- My carer has access to further information relevant to them, and understands which benefits they are also entitled to.
- My carer's role is respected and supported. They also feel valued and valuable, and neither of us feel alone.

The Alzheimer's Society report Dementia 2012⁸⁹, found that in a survey of people with dementia living at home:

- 47% of respondents felt that their carer is only sometimes (30%) or is not (17%) getting the support that they need to carry out their caring role.

19.1.4 Safety/safeguarding

No specific safety or safeguarding issues identified.

⁸⁷ Department of Health(2010) [Recognised, valued and supported: next steps for the Carers Strategy](#)

⁸⁸ Dementia Action Alliance (2010) [National dementia declaration](#)

⁸⁹ Alzheimer's Society (2012) [Dementia 2012: a national challenge](#)

19.1.5 Current practice

Contained within National Dementia Strategy⁹⁰ objective 7: Implementing the Carers' Strategy.

Markers of appropriate training are contained within the Department of Health's 'Common core principles for supporting people with dementia'⁹¹:

- Principle 6 Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice.

A survey of adult carers in England⁹² found that 54% of carers of people with dementia were 'extremely or very satisfied' with the support received by both they and the person they cared for. It also found that 36% of carers of people with dementia reported accessing breaks lasting more than 24 hours, whilst 47% accessed breaks lasting less than 24 hours. Overall quality of life was reported by carers of people with dementia as:

Could not be better	1%
Very good	9%
Good	20%
Alright	48%
Bad	15%
Very bad	4%
Could not be worse	2%

Key messages from SCIE research briefing 35⁹³ include:

- Carers of BME people with dementia may feel reluctant to ask for help, although support in the form of carers' groups and respite services may be appreciated. Different communities may have differing views about whether they wish these services to be culturally specific or mixed.

19.1.6 Current indicators

National Indicator 135 (VSC18)⁹⁴ - Carers receiving needs assessment or review and a specific carer's service, advice or information.

The 2012/13 Social Care Outcomes Framework⁹⁵ indicator 1D: Carer-reported quality of life.

The 2012/13 NHS Outcomes Framework⁹⁶ indicator 2.4: Health-related quality of life for carers.

⁹⁰ Department of Health (2009) [National Dementia Strategy](#)

⁹¹ 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](#).

⁹² NHS Information Centre(2010) [Personal Social Services survey of adult carers in England \(2009-10\)](#)

⁹³ SCIE (2011) [Research briefing 35: Black and minority ethnic people with dementia and their access to support and services](#)

⁹⁴ Data available from the [National Adult Social Care Intelligence Service](#) (NASCIS)

⁹⁵ Department of Health (2012) [Social Care Outcomes Framework 2012/13](#)

20 End of life care - Features of end of life care specific to people with dementia + Support and information for unpaid carers in the end of life care of people with dementia

20.1.1 Relevant guidance recommendations and proposed quality statement

Guidance recommendations	NICE CG42 1.10.1.4, 1.10.1.6 and 1.10.1.7 SCIE Guide 15 Please see page 22 of the prioritisation paper
Proposed quality statement	Services supporting people with dementia provide training to staff and carers in end of life care specific to people with dementia.
Draft quality measure	<p>Structure: Evidence of local arrangements to provide staff and carers with training in end of life care specific to people with dementia.</p> <p>Process:</p> <p>a) Proportion of carers of people with dementia who are trained in end of life care specific to people with dementia.</p> <p>Numerator – the number of carers in the denominator who have received training in end of life care specific to people with dementia.</p> <p>Denominator – the number of carers of people with dementia.</p> <p>b) Proportion of staff supporting people with dementia who are trained in end of life care specific to people with dementia.</p> <p>Numerator – the number of staff in the denominator who have received training in end of life care specific to people with dementia.</p> <p>Denominator – the number of staff supporting people with dementia.</p> <p>Outcome:</p> <p>a) Evidence that staff feel competent in providing end of life support to people with dementia.</p> <p>b) Evidence that carers feel competent in providing end of life support to people with dementia.</p>

20.1.2 Effectiveness evidence

NICE clinical guideline 42 details evidence from retrospective case-note studies in the UK in psychiatric and acute hospital wards that have suggested there is inadequate palliative care for people with dementia.

⁹⁶ Department of Health (2012) [NHS Outcomes Framework 2012/13](#)

SCIE guide 15 includes a specific section on end of life care (Specialist services). The report recognises that the task of enabling staff to support people who are dying should not be underestimated, 'knowing how to provide comfort requires insight into the whole landscape of a dying patient's experience'.

20.1.3 User experience of services

NICE clinical guideline 42 identified a range of research studies that looked at the end of life experience for people with dementia. In a retrospective survey of carers, the most commonly reported symptoms suffered by the person with dementia in the last year of life were confusion (83%), urinary incontinence (72%), pain (64%), low mood (61%), constipation (59%) and loss of appetite (57%). A similar picture emerges from a synthesis of the research evidence in this area, and a survey of care more generally for people with dementia in private and NHS facilities in the UK. These more recent reviews suggest the situation for service users has not greatly improved. The guideline makes specific recommendations for further research into this area of care.

Desired outcomes for people with dementia were described in the National Dementia Declaration⁹⁷. These included:

- I will die free from pain, fear and with dignity, cared for by people who are trained and supported in high quality palliative care.

20.1.4 Safety/safeguarding

None identified.

20.1.5 Current practice

Contained within the National Dementia Strategy⁹⁸ objective 12: Improved end of life care for people with dementia

SCIE guide 15 discusses the challenge for care providers in supporting people with dementia during this stage. The report recognises that death is inevitably nearer for older people and it is therefore an issue for many people providing health and social care services for this group. It may be easy for staff to overlook the personal experience of those they support who are nearing the end of life. The report supports the need for staff to receive training and support to enable them to listen effectively and respond appropriately to those they support.

The End of Life Care Strategy⁹⁹ states that 'End of life' care should be included in induction programmes, in continuing professional development

⁹⁷ Dementia Action Alliance (2010) [National dementia declaration](#)

⁹⁸ Department of Health (2012) [Quality Outcomes for people with dementia: building on the work of the National Dementia Strategy](#)

and in appraisal systems. The strategy suggests that practice should aim to enable people to keep control and to minimise suffering through good clinical and social care. The feeling for the individual of being a burden, whether it is real or perceived, will be lessened by the provision of good support for carers. This should include carers assessment, involvement in decision making, information about the person's condition and about services, practical and emotional support and bereavement support.

20.1.6 Current indicators

None identified.

⁹⁹ Department of Health (2008) [End of Life Care Strategy](#)