

**Social care quality standards stakeholder briefing workshop
Care of people with dementia**

**Monday 31st October 2011 10:00-12:30
NICE, Level 1A, City Tower, Piccadilly Plaza, Manchester M1 4BD**

Stakeholder briefing workshop notes

Introduction

A workshop was held with a range of stakeholders from the social care and health community on the 31st October 2011. The purpose of the workshop was to set out the proposed scope of the social care quality standard on the care of people with dementia. A draft “topic overview” prepared by the quality standards team was used as the basis of the workshop discussions.

The workshop was designed to fulfil the following key objectives, to:

1. Provide stakeholders with information on the interim process being used to develop quality standards for social care
2. Provide stakeholders with information on how the existing processes have been adapted for social care and the purpose of the pilots in testing existing processes
3. Provide stakeholders with information on the draft scope of the quality standards and the parameters within which the standards can be developed
4. Seek advice from stakeholders on the priority areas for consideration in the scope of the quality standard to be drafted by the Topic Expert Group.
5. Seek advice from stakeholders on the language, sources of information and policy used in the Topic Overviews
6. Seek advice from stakeholders on the potential constituency of the Topic Expert Group.

Following presentations from the NICE team, discussion groups were held focussing on key questions highlighted in the topic overview. A summary of key themes raised in the discussion groups is presented in this report.

Appendices

Appendix A: NICE quality standard for dementia (published 2010) and Key Priorities for Implementation from NICE/SCIE clinical guideline 42

Appendix B: Potentially relevant NICE and SCIE guidance that could be used to support the social care quality standard

Appendix C: Other documents that could be used to support the social care quality standard

Appendix D: List of participating stakeholder organisations

Appendix E: Timeline of next steps

1.1 Proposed focus and population of the quality standard

The referral from the Department of Health is to develop a social care quality standard on the 'care of people with dementia'.

The topic overview presented at the workshop proposed to use the following parameters as the basis for the scope of the quality standard:

- **Focus:** Support and care provided or commissioned by local authorities (including care funded through personal budgets).
- **Population:** All people with dementia cared for at home or in nursing or residential care settings.
- **Excluding:** Hospital inpatient care.

Questions on the proposed scope

1.2 Question 1

Should the proposed focus and population be changed? In what way?

1.2.1 Focus

Self-funded and commissioned care

The main point raised by the workshop groups was the importance of widening the focus to include self-funded care. It was noted that in a large proportion of cases, care provided for people with dementia was self-funded and did not necessarily have any local authority funding input.

Other groups who input into dementia care

One group asked for clarity as to whether the voluntary/not for profit sector would be included in the settings for the quality standard. This group also felt that the importance of advocacy for this group should not be overlooked. Another group noted that it might be useful to make a distinction between specialised and non-specialised care.

Training and workforce planning

One group noted that training and consistency of training is important as well as workforce planning and identifying the needs of staff whose first language is not English.

1.2.2 Population

One group supported the inclusion of those being cared for in both residential and domiciliary care, and also highlighted that most dementia care is provided in people's homes. Another group was pleased that the population descriptor had been updated from 'elderly mentally ill'.

Participants also felt that it was important to recognise comorbidities and physical health needs to people with dementia.

Participants requested that the quality standards team consider whether the following groups and/or settings were included:

Those without a formal diagnosis

Two of the groups raised whether those without a clinical diagnosis of dementia would be covered by the quality standard and one group suggested that the term *cognitive impairment* may be more suitable as it includes those without such a diagnosis.

Carers

Support, information and advocacy for carers, both formal and informal, should be included, especially considering the complexity of caring for people with dementia and that interventions outlined in the quality standard may focus on provision by informal carers. It was also noted that it was important to focus on all care, regardless of whether it is paid for or not. Personal assistants paid for through personal budgets should be included.

Settings

The following settings were also suggested for inclusion in the quality standard:

- Hospices
- Cottage hospitals
- Prisons
- Daycare for people with dementia

Entry into dementia care

One group also discussed the importance of considering the point of entry into dementia care as this has a high impact on the services required.

1.2.3 Exclusions

Hospital in-patient care

Participants felt that the exclusion of hospital in-patient care could be problematic and asked for clarification on what this meant for the quality standard. The quality standards team were asked to clarify whether the following would be included:

- Transition of people into and/or out of hospital
- People with dementia accessing hospital services for reasons other than dementia
- Continuing care post-discharge from hospital
- Coordination between health and social care

1.2.4 Other comments

One group felt that the title Living well with dementia may better capture what the QS can help to achieve and suggested the title was reconsidered as this may be more acceptable to people with dementia.

1.3 Question 2

How will this social care quality standard complement the published [NICE dementia quality standard](#)?

Workshop participants were presented with an overview of the presentation and components of existing NICE healthcare quality standards, as well as the quality statements from the dementia quality standard (see appendix A) and were asked to consider how this social care quality standard could complement the existing healthcare quality standard.

The following key points and questions were raised by participants in relation to this question:

Links to existing standards

- All groups felt that it was important to identify how the social care quality standard would link with the existing healthcare quality standard. It was felt that this could be achieved by:
 - Including some existing statements in the social care quality standard, but revisiting quality measures
 - Ensuring that together both quality standards cover the entire care pathway
 - Amending the language used in the healthcare statements to reflect the audience
 - Understanding the importance of choice in the social care arena
 - Noting that the healthcare quality standard covers some of the stages of dementia care before the amount of social care required is significant
- One group noted the importance of linking with the quality standard on end of life care which was due to be published.
- Participants noted that importance of linking with CQC's essential standards of quality and safety as well as other standards being produced by, for example, the Royal College of Nursing and the Royal College of Psychiatrists.
- There are issues around integration of care pathways and agencies and continuity of care which separate standards may tend to overlook.

Format and intended audience

- One group queried whether the social care quality standards would be web-based only, as this could be disadvantageous for targeting frontline staff and informal carers. It was noted that "Caring with confidence" is a good example of information for informal carers.
- It was also suggested that once the audience of the quality standard had been identified, it would become clearer what it should look like. For instance, it was suggested that providers need a detailed steer on what to provide.

Aspirational but achievable standards

- It was noted that whilst healthcare quality standards are intended to be aspirational but achievable, this may be limiting for social care, as that which Social care quality standards stakeholder briefing workshop notes Care of people with dementia

is achievable may not provide the quality of care that is ideal. There is a need to be clear what the starting point is, i.e. is this about a quality standard aiming to demonstrate the best care for the money available or high-quality care regardless of cost?

Comparison with existing healthcare quality standard

The following points were raised in relation to the existing healthcare quality standard. In social care:

- Statements should be about individual service user needs
- Self-management is different compared to other health conditions
- Carers need to have access to training and support
- There is a responsibility to people with dementia regarding services and supporting and empowering people
- Person-centred care is now known as relationship-centred care

2.1 Outcomes desired by people with dementia and their carers

The diagram below is taken from the Department of Health's 'Quality outcomes for people with dementia'¹ and demonstrates the outcomes (specific to people with dementia) that could provide a focus in the development of the social care quality standard.



Questions on outcomes, audience and links with other standards

2.2 Question 3

Do these outcomes provide a useful structure to identify the areas that the quality standard should address?

- Participants were generally supportive of the use of the Department of Health quality outcomes for people with dementia especially as they demonstrate a service user perspective. They are also useful as tools for professionals to understand a person's needs and empathise with these
- One group noted that any 'map' needs to work for the individual as failure points will be different, as will the impact of any failure. Furthermore, some of the meaning in the outcomes focuses on dementia, rather than on the person's life. This group also queried whether the outcomes were evidence-based

¹ Department of Health (2010) [Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy](#).

- Some participants felt that whilst these outcomes are a useful starting point, they may not be a comprehensive source of outcomes for the whole quality standard. Additionally, it was felt that additional detail may be required within overall themes.
- One group noted that some outcomes, such as “I can enjoy life” might be difficult to deliver and/or measure. This could be refined by considering how people are supported to live as they want to by focussing on what is meaningful to the individual
- Participants also noted that these outcomes appear to be designed to work for those people who understand their diagnosis and that outcomes may be different for those who are not able to understand their diagnosis.
- One group noted that by focussing the social care quality standard on people’s “lives”, this would differentiate from and complement the existing healthcare quality standard
- One group noted that it was important to recognise local reporting and accountability to local communities
- Participants outlined that these outcomes would be affected by:
 - Training of staff to make them dementia aware
 - Treating patients with dignity
 - Improved quality of life
 - More choices for the patient and carer
 - Allowing service users to review the quality of services

2.3 Question 4

Are there other outcomes that should be considered?

Participants suggested the following areas for additional outcomes which could be considered:

- Understanding me as an individual
- People are supported to make decisions
- People’s autonomy and wishes are respected

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- My carers understand the things that are important to me
- Personal hygiene
- Family awareness of routes into care and available/possible care and support
- Advocacy and/or access to proxy voice
- Spiritual, cultural and religious
- Compassion and kindness
- Use of medication and over medication
- Management of behaviour
- Supporting to people to live as they want to
- Integration and coordination of care that enables people to live their lives as they want to
- Human rights and mental capacity
- Feeling and being safe
- Physical health
- Assistive technologies (Independence)
- Seamless, integrated care

One group noted that the Dementia Action Alliance expands on the Department of Health outcomes and that this may be a useful resource. Another group felt that by mapping these outcomes to a “journey of care” it may be possible to identify gaps in the outcomes noted. It was suggested that using “life histories” may enable other outcomes to be identified.

One group noted that the 7 outcomes that are highlighted as important to service users should be included.

One group noted that DH Outcome Box 1 assumes diagnosis and although diagnosis is not made in social care, early diagnosis can be influenced by social care processes (e.g. staff identification, referral etc.) The group also noted that early diagnosis links to later outcomes, specifically End of life care planning.

One group wondered how the Adult Social Care Outcomes Toolkit (ASCOT) would relate to the Department of Health outcomes. The group noted that ASCOT measures social care related quality of life (as EQ5D is not considered an appropriate tool for social care) and can provide information on cost effectiveness. The group asked whether the ASCOT was condition specific and noted that although work had been done to validate the tool, this has not been done for people with dementia.

Participants also raised the following issues in relation to this:

- Ensure that quality in social care is not an 'add on' to health care
- Maintain involvement of people grounded in social care to give credibility and ensure effectiveness
- Despite changing priorities in policy, need to ensure high quality services, not just compliance
- Pay in the sector is an issue which limits quality
- Need to link with the existing Excellence scheme
- Considering the track record of money following quality, there will be an added incentive for improving quality of practice
- The use of 'aspirational' outcomes in the system is difficult
- Quality and what it looks like should be defined and these outcomes currently outline what quality looks like

2.4 Question 5

Do the aspects of personalisation need to be made more explicit?

- Participants noted the importance of recognising the heterogeneity of this group and that there should be a greater focus on personalisation and choice, and that this is partly about staff getting to know individuals, rather than thinking of people as a "person with dementia". Also, it is important to move towards outcomes that focus on the individuals, as people have changing needs as their illness progresses, and at different ages. One way of achieving this could be to focus on relationship-centred care.
- One group noted that workforce issues were really important for the quality standard and that a focus on the individual may cause these issues to be

ignored and/or assumed. It was also noted that occasionally, individual and workforce considerations are conflicting and that this needed to be addressed.

- One group noted that the use of personal budgets to support and prolong care in settings such as own home should be considered within scope.
- One group felt it was important for the quality standard to be flexible enough to recognise the variation in how care is provided, for example where daycare is run from a pub.

2.5 Question 6

What are the most important areas to address and who needs to be influenced?

Participants considered the following as the most important areas to address in the quality standard:

- Workforce
- Enabling people to live their lives
- Coordination between and integration of health and social care activities
- Navigation through the care pathway
- Communication and quality of information
- Dignity and respect (following on from 'Hidden in Plain Sight')
- Dimensions of quality (e.g. experience, safety, effectiveness and cost/value for money)
- Choice of residential care – balance between preference of the individual, family and local commissioner and understanding how funding affects this decision (Note: Commissioning of residential care is moving towards providing services for people with dementia as the main population)
- End of life care
- Resuscitation
- Disempowerment
- Diagnosis and people's responses

- Domestic care/care in the home/personal assistance in terms of provision, training and accessibility

One group noted that given the multiplicity of providers, the challenge will be to achieve consistency in quality as targets and processes for achieving quality will be different across providers.

3.1 Evidence Sources

A list of evidence sources presented at the workshop is included in Appendix B. The following questions relate to this list.

3.2 Questions 7 to 9:

- **Are these evidence sources appropriate?**
- **Can you suggest other NHS Evidence accredited sources?**
- **By only using NHS Evidence accredited sources are there other resources we are not including?**
- Participants showed a general concern that the lack of research funding in social care may mean that there is a gap in the associated evidence base (Dementia clinical guideline). It was however noted that guidelines can be based on expert opinion in the absence of evidence and that other quality standards and guidance could be used to underpin the dementia social care quality standard
- Participants suggested highlighting those areas where the evidence base has been further developed beyond the guideline, even if not being reviewed. This was discussed in the context of the publication date of the original guideline being 2006, and that the social care perspective has changed since then with the introduction of personalisation and the Mental Capacity Act. As a result, the review of the clinical guideline was discussed and there was a query around the update of the guideline, and whether this would happen during production of the quality standard.
- One group noted that the longer term issue around social care research needs to be recognised and influenced where possible
- Participants noted that including the voice of people living with dementia, even through narratives, needed to be heard. It was also noted that if only NHS evidence accredited sources are used, people's experience of care may be missed. One group suggested that sources that might be missed included the Dementia Activism project working with Ruth Bartlett, the University of Bradford and the University of Southampton in Essex, which captures experience of care.

- One group felt that the important issue for the TEG is to consider what is essential evidence and what will encourage excellence when developing the quality standard and determining evidence sources.
- One group noted that it was important to look at existing standards and unpick quality elements in those standards to fit with the quality standard.
- One group noted a request that NICE should not only produce web-based products

4.1 Other documents

A list of other documents presented at the workshop is included in Appendix C. This includes documents on the policy context as well as national reports and reviews. The following questions relate to this list. Workshop attendees were also asked to submit any further relevant document references to NICE following the workshop

4.2 Questions 10 to 12:

- **Are these policy documents appropriate?**
- **Can you suggest other important sources?**
- **Are there any other reports, audits, surveys or reviews specific to the care of people with dementia that would be of use?**

Participants identified the following additional areas and resources where papers could be useful:

- Report from summit on dementia social care research
- Davies and Knapp paper on Production of welfare
- Dementia care mapping tool
- Description of different types of death (published) – death post M.I., death post dementia
- End of life care
- Personalisation
- Choosing Health (2004)

- Adult social care outcomes framework (April 2011)
- Department of Health policy on equalities
- University of Sterling paper on using health technology (or an English equivalent)
- ['The £20 billion question - An inquiry into improving lives through cost effective dementia services'](#)
- Nuffield Bioethics report on Dementia
- POPS pilot – prevention in older people
- Martin – understanding recovery approach to dementia care
- Dementia within both a clinical and social care focus

Qualitative research into views of people with dementia

5.1 Topic Expert Group constituency

Participants at the workshop were asked which categories of people should be invited to apply for membership of the Topic Expert Group (TEG) to formulate the quality standard.

Suggestions for TEG members included:

- Local authority representation
- Education and training
- Researcher
- Carer
- People involved in social care education
- Health service commissioner
- Acute sector representatives
- Voluntary sector (campaigners and service providers)

Further comments on the TEG constituency included:

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- Maximum number of 12 TEG members could restrict representation against such a wide scope, but acknowledgement that there needs to be a balance between representation and workability.
- TEG composition should reflect the areas identified within question 3 of the breakaway discussion (physical health, safety, independence - assistive technologies, integrated care) and the diagram in the topic overview paper.
- Thought should be given to who is required for development of the QS at the TEG stage and who is required to give input around its application within the field testing stage.
- Suggestion that members need to be able to 'keep it real', i.e. recognise what is achievable for services in reality.
- Ensuring that staff at all levels are engaged, including PA's and thought needed to be given to promoting the QS to them and gaining their commitment to support it.
- Suggestion that TEG members are identified who can represent various angles, e.g. a carer who is involved in social care education and research.
- Term 'lay member' should not be labelled as such alongside 'professional member' as there is an implication that the person is less of an expert, whereas they may have vast experience.
- Field work / consultation processes need to be adapted to support engagement of people with dementia, e.g. working with groups.
- TEG constituency should address diversity
- The crossover between health and front line social services needs to be better reflected.
- Can it better reflect that social care will be the majority?
- Is a councillor going to have enough specific knowledge?
- How would LINK networks be considered?

Appendix A NICE quality standard for dementia²

Below is the recently published NICE [quality standard for dementia](#) (published 2010). This quality standard is based on the NICE/SCIE dementia guideline CG42. The key priorities for implementation from CG42 are also presented on page 11 to demonstrate the types of recommendations used to inform the development of this quality standard.

1	People with dementia receive care from staff appropriately trained in dementia care.
2	People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.
3	People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.
4	People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care that identifies a named care coordinator and addresses their individual needs.
5	People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of : <ul style="list-style-type: none"> • advance statements • advance decisions to refuse treatment • Lasting Power of Attorney • Preferred Priorities of Care.
6	Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.
7	People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.
8	People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.
9	People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.
10	Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.

² Available from www.nice.org.uk/guidance/qualitystandards

NICE/SCIE clinical guideline 42 (Dementia)³ key priorities for implementation

The recommendations below are the key priorities for implementation taken from the NICE/SCIE guideline on dementia. These were used as a starting point in the development of the NICE quality standard for dementia.

Non-discrimination

- People with dementia should not be excluded from any services because of their diagnosis, age (whether designated too young or too old) or coexisting learning disabilities.

Valid consent

- Health and social care professionals should always seek valid consent from people with dementia. This should entail informing the person of options, and checking that he or she understands, that there is no coercion and that he or she continues to consent over time. If the person lacks the capacity to make a decision, the provisions of the Mental Capacity Act 2005 must be followed.

Carers

- Health and social care managers should ensure that the rights of carers to receive an assessment of needs, as set out in the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004, are upheld.
- Carers of people with dementia who experience psychological distress and negative psychological impact should be offered psychological therapy, including cognitive behavioural therapy, conducted by a specialist practitioner.

Coordination and integration of health and social care

- Health and social care managers should coordinate and integrate working across all agencies involved in the treatment and care of people with dementia and their carers, including jointly agreeing written policies and procedures. Joint planning should include local service users and carers in order to highlight and address problems specific to each locality.
- Care managers and care coordinators should ensure the coordinated delivery of health and social care services for people with dementia. This should involve:

³ Available from www.nice.org.uk/guidance/CG42

- a combined care plan agreed by health and social services that takes into account the changing needs of the person with dementia and his or her carers
- assignment of named health and/or social care staff to operate the care plan
- endorsement of the care plan by the person with dementia and/or carers
- formal reviews of the care plan, at a frequency agreed between professionals involved and the person with dementia and/or carers and recorded in the notes.³

Memory services

- Memory assessment services (which may be provided by a memory assessment clinic or by community mental health teams) should be the single point of referral for all people with a possible diagnosis of dementia.

Structural imaging for diagnosis

- Structural imaging should be used in the assessment of people with suspected dementia to exclude other cerebral pathologies and to help establish the subtype diagnosis. Magnetic resonance imaging (MRI) is the preferred modality to assist with early diagnosis and detect subcortical vascular changes, although computed tomography (CT) scanning could be used. Specialist advice should be taken when interpreting scans in people with learning disabilities.

Behaviour that challenges

- People with dementia who develop non-cognitive symptoms that cause them significant distress or who develop behaviour that challenges should be offered an assessment at an early opportunity to establish the likely factors that may generate, aggravate or improve such behaviour. The assessment should be comprehensive and include:
 - the person's physical health
 - depression
 - possible undetected pain or discomfort
 - side effects of medication
 - individual biography, including religious beliefs and spiritual and cultural identity
 - psychosocial factors
 - physical environmental factors
 - behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers.

Individually tailored care plans that help carers and staff address the behaviour that challenges should be developed, recorded in the notes and reviewed regularly. The frequency of the review should be agreed by the carers and staff involved and written in the notes.

Training

- Health and social care managers should ensure that all staff working with older people in the health, social care and voluntary sectors have access to dementia-care training (skill development) that is consistent with their roles and responsibilities.

Mental health needs in acute hospitals

- Acute and general hospital trusts should plan and provide services that address the specific personal and social care needs and the mental and physical health of people with dementia who use acute hospital facilities for any reason.

Appendix B Potentially relevant NICE and SCIE guidance that could be used to support the social care quality standard

The following list demonstrates the NHS Evidence accredited guidance relevant to people with dementia that could be used as the evidence sources to develop the statements for the social care quality standard:

NICE [quality standard for dementia](#) (2010).

[Mental wellbeing and older people](#). NICE public health guidance 16 (2008). Available from www.nice.org.uk/Guidance/PH16

[Dementia](#). NICE/SCIE clinical guideline 42 (2006; NHS Evidence accredited).

Appendix C Other documents

Policy context for the social care quality standard

The following list demonstrates the policy context relevant to people with dementia that might need to be considered during the development of the social care quality standard:

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

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

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

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

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

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

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

Department of Health (2010) [NHS Outcomes Framework.](#)

Department of Health (2010) [Dignity in care.](#)

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

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

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

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

National reports and reviews

The following list demonstrates other national reports and reviews relevant to people with dementia that might need to be considered during the development of the social care quality standard:

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Care Quality Commission (2011) [The state of health care and adult social care in England. An overview of key themes in care in 2009/10](#)

Care Quality Commission (2011) [What standards to expect from the regulation of your care home. An introduction to important changes to how adult social care services are regulated](#) This booklet is aimed at the public in England

Department of Health (2011) [Service specification for dementia: better care at home, and in care homes](#)

Healthcare at Home (2011) [Understanding out of hospital dementia care](#)

Mental Health Foundation (2011) [Personalisation and Dementia: A practitioner's guide](#)

Mental Health Foundation (2011) [Personalisation and dementia: a resource for trainers on self-directed support for people living with dementia](#)

Skills for Care (2011) [Meeting the workforce regulations: Skills for Care advice on CQC's workforce-specific outcomes; 14 and 25](#)

Social Care Institute for Excellence (2011) [Black and minority ethnic people with dementia](#) Research briefing 35.

Think Local Act Personal Partnership. Available from www.thinklocalactpersonal.org.uk

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

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

Audit Commission (2010) [Under pressure: Tackling the financial challenge for councils of an ageing population](#)

Care Quality Commission (2010) [Guidance about compliance. Essential standards of quality and safety. What providers should do to comply with the section 20 regulations of the Health and Social Care Act 2008](#) See the [CQC](#) website for further info, including quick reference guides.

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

House of Commons Committee of Public Accounts (2010) [Improving dementia services in England: an interim report](#)

Joseph Rowntree Foundation (2010) [Equality and Diversity and Older People with High Support Needs](#)

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

National End of Life Care Programme (2010) [Care towards the end of life for people with dementia: an online resource guide](#)

Personal Social Services Research Unit (2010) [Measuring the outcomes of care homes: final report](#)

Personal Social Services Research Unit, Age UK (2010) [The impact of a tightening fiscal situation on social care for older people](#)

Personal Social Services Unit Research (2010) [Projections of demand for residential care for older people in England - Report for BUPA](#)

Royal College of Psychiatrists (2010) [The need to tackle age discrimination in mental health. A compendium of evidence](#)

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

Social Care Institute for Excellence (2010) [Age equality and age discrimination in social care: An interim practice guide](#). SCIE guide 35.

Social Care Institute for Excellence (2010) [Personalisation briefing: Personalisation and mental capacity](#) At a glance 33.

Social Care Institute for Excellence (2010) [Personalisation briefing: Implications for nursing homes](#) At a glance 20.

Care Quality Commission (2009) [Review of healthcare for people living in care homes](#)

Centre for Policy on Ageing (2009) [Ageism and age discrimination in mental health care in the United Kingdom. A review from the literature](#)

Healthcare Commission (2009) [Equality in later life: a national study of older people's mental health services](#)

Ipsos Mori (2009) [Follow-up research on dementia services. Research prepared for the National Audit Office](#)

Joseph Rowntree Foundation (2009) [Inquiry into the dementia care skills of social care staff supporting people with dementia in care homes and their own homes](#)

Mental Health Foundation (2009) [All things being equal: Age equality in mental health care for older people in England](#)

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Royal College of Psychiatrists Faculty of Old Age Psychiatry (2009) [Links Not Boundaries: Service Transitions for People Growing Older with Enduring or Relapsing Mental Illness](#)

Social Care Institute for Excellence (2009) [Personalisation briefing: Implications for residential care homes](#) At a glance 17

All-Party Parliamentary Group on Dementia and Alzheimer's Society (2008) [Always a last resort: inquiry into the prescription of antipsychotic drugs to people with dementia living in care homes](#)

Commission for Social Care Inspection (2008) [See me, not just the dementia: understanding people's experiences of living in a care home](#)

House of Commons Committee of Public Accounts (2008) [Improving services and support for people with dementia](#)

Institute for Public Policy Research (2008) [Older People and Wellbeing](#)

Joseph Rowntree Foundation (2008) [Supporting older people in care homes at night](#)

Personal Social Services Research Unit (2008) [Age Discrimination in Mental Health Services](#)

Age Concern England, Mental Health Foundation (2007) [Improving services and support for older people with mental health problems: the second report from the UK Inquiry into Mental Health and Well-Being in Later Life](#)

Alzheimer's Society (2007) [Home from home: a report highlighting opportunities for improving standards of dementia care in care homes](#)

Care Services Improvement Partnership (2007) [Integrated mental health services for older adults: a service development guide](#)

Help the Aged, National Care Homes Research and Development Forum (2007) [My home life: quality of life in care homes - a review of the literature](#)

National Audit Office (2007) [Improving Services and Support for People with Dementia](#)

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Appendix D Stakeholders represented at the workshop

Action on Hearing Loss

Age UK

Alzheimer's Society

Anchor Trust

Association of Directors of Adult Social Services

British Association of Social Workers

British Geriatrics Society

British Psychological Society

College of Occupational Therapists

Crossroads Care

Dementia UK

Department for Work and Pensions

Department of Health

English Community Care Association

Equality and Human Rights Commission

Gayle J Booth (Consultancy)

Local Government Group

London School of Economics

NAPA – National Association for Providers of Activities

NHS Yorkshire and the Humber

Nursing Homes Medical Practice & Care Home Services, GGCNHS

PSS

Registered Nursing Home Association

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Royal College of Nursing

Royal College of Speech and Language Therapists

Sheridan Care Ltd.

Skills for Care

Staffordshire LINK

Standing Commission on Carers

The Partnership in Care

Trafford Carer's Centre

University of Manchester

University of York

Appendix E Next steps

November 2011	Adverts for Topic Expert Group members go live on NICE website
January 2012	Topic Expert Groups convened and scopes of two topics drafted
March/April 2012	Engagement with stakeholders on pilot topic scopes
May 2012	TEGs draft quality statements. Publication of pilot topic scopes
16 th August to 16 th October 2012	Consultation on draft quality standards with stakeholders and fieldwork carried out
November 2012	TEGs consider consultation comments and redraft quality standards
December 2012	Final fieldwork report published
2 nd April 2013	Publication of final quality standards

NB. All dates are provisional and are subject to confirmation.