
Field testing of the pilot social care quality standard on the care of people with dementia: Annexes

October 2012



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Annex A: Equality Impact Assessment

Results and conclusion

The primary **result** of this equality impact assessment is recognition that although 'diversity, equality and language' are highlighted at the front of the standard there is a need to consider making some adjustments within the standard itself to avoid alienating certain groups. In particular, there is a suggestion to provide guidance and support to aid those implementing the standard to consider the differing needs and circumstances of some groups and to tailor their handling of situations appropriately.

There was a mixed view from participants in the research, with some feeling that the standard was inclusive in its current form and others feeling that more could be done to ensure it was inclusive. There was recognition that there were important barriers that affect minority groups' access to dementia care services, and that this may need further acknowledgement within the standard.

In particular, suggestions were made to improve the inclusivity of the standard with respect to people affected by dementia in the LGBT community, the learning disability community and minority ethnic communities who often face different issues and circumstances. There is a need for the standard to be sensitive to this and ensure that wording and implementation is inclusive of different circumstances and does not alienate or create barriers to engagement.

In terms of improvements to mitigate against uneven impacts upon these groups it was suggested that guidance associated with the standard could consider how an individual statement related to various minority groups. With regard to those who do not have access to the traditional family network, it was suggested that the word 'carer' needs more consideration. In particular, in relation to cases where it may have to include a paid employee as an advocate as they may be the one who mainly cares for them. It was felt necessary to reflect this in the standard and within any guidance produced.

There were broader concerns over cultural norms in relation to recognising dementia, seeking help and accepting support in some communities. A sense that some communities do not routinely access health, social care or voluntary sector support. As a result, there is an opportunity to be more proactive to encourage contact with these groups. Related to this was the need for cultural awareness amongst staff to be able to recognise the issues facing some members of the community.

The reference to people having a right to an interpreter or advocate may be unclear as to whether this was in relation to the condition or English not being the first language. It was felt this ambiguity should be addressed.

Workforce participants suggested the need for ensuring people with dementia and their carers were aware of the standard and clear about expectations. However, there was some concern

that people may be disappointed as raised expectations may not be met due to service cut backs.

Guidance and training should be developed to raise awareness amongst practitioners, perhaps with examples of good practice and case studies to “bring the document to life”. The ‘Making it real’ approach was cited as a positive way to develop these. It was also felt that the standard needed to sit within the broader context of government policy, alongside health and access issues.

One interviewee did raise concern over the lack of a statement specifically for carers, although there was recognition that this might be inappropriate in the context of this work.

It was also commented that there is a stigma associated with dementia more generally within all communities, and work needs to be done to change this and allow the aspiration of the standard to be achieved. There was a suggestion that people who live with dementia could deliver training to staff to address some of the stereotypes and stigma associated with the condition.

The fact that NICE have undertaken such a wide consultation (including the Skills for Care and Dementia UK research) demonstrates a willingness to consider the views of people affected by dementia and the workforce involved. The points raised as part of the research in relation to equality and diversity suggest that with some relatively minor amendments to the standard and/or provision of guidance and support for implementation could overcome any concerns highlighted.

The points raised above are explored further in Chapter 6 of the report and the full EqIA below.

1. Define the aims of the standard

Title of document	NICE Quality Standard for Dementia
Strategic Outcome	There are thirteen quality statements, supported by quality measures which are intended to improve the structure, process and outcomes of health and social care in relation to dementia.
Coverage	All relevant agencies involved in the whole dementia care pathway as well as people living with dementia and their carers. It covers all care provided by health and social care staff in direct contact with people with dementia in hospital, community, home-based, group care, residential or specialist care settings.
Responsible for Document	National Institute for Health and Clinical Excellence (NICE)

What is the purpose of the proposed standard?	To improve the structure, process and outcomes of health and social care in relation to dementia.
Who is affected by the standard or who is intended to benefit from the proposed standard and how?	Affects all relevant agencies involved in the whole dementia care pathway as well as people living with dementia and their carers. Within agencies this includes commissioners, employers, managers and the workforce themselves. It covers all care provided by health and social care staff in direct contact with people with dementia in hospital, community, home-based, group care, residential or specialist care settings. The core aim is to improve the outcomes of people living with dementia and their carers through improving processes in relation to health and care provision.
How will the standard be put into practice and who will be responsible for delivering it?	The standard has taken the 11 key priorities for implementation from the NICE-SCIE

	<p>clinical guideline 42 (CG42), which were developed by the Topic Expert Group (TEG) into draft quality statements. A total of 18 draft statements were presented for consultation. Following receipt of feedback the TEG prioritised 13 statements for inclusion into the final quality standard.</p> <p>This is out for formal consultation at the present time. Further independent research has been undertaken amongst employers, the workforce, people living with dementia, their carers and representative bodies to review and comment on the standard.</p> <p>The standard and quality measures are not compulsory or intended to be a new set of targets or mandated indicators for performance. They are however there to support the improvement of outcomes of people living with dementia and their carers through improving processes in relation to health and care provision.</p> <p>The intention is for the standard and quality measures to inform and guide all relevant agencies involved in the whole dementia care pathway as well as people living with dementia and their carers.</p>
<p>How does the standard fit into our wider or related policy initiatives?</p>	<p>The standard is part of the NICE Quality Standards Programme and is held within the Implementation Directorate.</p> <p>Related policy documents include:</p> <p>National Audit Office, 'Improving dementia services in England: an interim report' (2010)</p> <p>Department of Health, 'The use of antipsychotic medication for people with dementia: Time for action' (2009)</p> <p>Department of Health, 'Living well with dementia: a national dementia strategy' (2009)</p> <p>National Audit Office, 'Improving services and support for people with dementia'</p>

	(2007)
Do you have a set budget for this work?	Not relevant

2. What do you already know about the diverse needs and/or experiences of the target audience?

The target audiences affected by the standard are:

- people living with dementia and their carers
- commissioners
- organisational employers
- workers in the sector

The audiences above have been specifically targeted as part of the research project undertaken by Skills for Care and Dementia UK. In addition, Skills for Care have access to statistics and other research in relation to a number of the protected characteristics involved.

Do you have information on	
Age	Yes
Disability	Yes
Sex	Yes
Pregnancy	Yes
Maternity	Yes
Sexual orientation	Yes
Race	Yes
Religion and Belief	Yes
Gender reassignment	Yes

Age	<p>NMDS-SC Statistics for workforce profile.</p> <p>Office of National Statistics for population profile.</p> <p>Numerous opportunities for engagement, research studies and consultations over the years with employers, the workforce and people who use services.</p>
Disability	<p>NMDS-SC Statistics for workforce profile</p> <p>Office of National Statistics for population profile</p> <p>Numerous opportunities for engagement, research studies and consultations over the years with employers, the workforce and people who use services.</p>
Sex	<p>NMDS-SC Statistics for workforce profile.</p> <p>Office of National Statistics for population profile.</p>

	<p>Numerous opportunities for engagement, research studies and consultations over the years with employers, the workforce and people who use services.</p>
Pregnancy	<p>Not collected on NMDS-SC.</p> <p>Office of National Statistics for population profile.</p>
Maternity	<p>Not collected on NMDS-SC.</p> <p>Office of National Statistics for population profile and labour market incidence.</p>
Sexual orientation	<p>Not collected on NMDS-SC.</p> <p>Office of National Statistics for population profile.</p> <p>Some of the more general research has captured the views of LBGT community with increasing use as a demographic.</p>
Race	<p>NMDS-SC Statistics for workforce profile.</p> <p>Office of National Statistics for population profile.</p> <p>Numerous opportunities for engagement, research studies and consultations over the years with employers, the workforce and people who use services particularly in relation to Recruitment & Retention strategies and Migration Advisory Committee submissions.</p>
Religion and Belief	<p>Not collected on NMDS-SC.</p> <p>Office of National Statistics for population profile.</p> <p>Some of the more general research has captured the views of religious communities, but often as part of race-based research analysis, which creates a potential risk of missing religious minorities and the non-religious in some communities.</p>
Gender reassignment	<p>Not collected on NMDS-SC.</p> <p>Office of National Statistics for population profile.</p>

3. Do you have enough information to help you understand the diverse needs and/or experiences of the target audience?

If not, what else do you need to know?

Age	Do you have enough information to proceed?
	Significant knowledge in relation to service user needs by age band and increasing knowledge in relation to workforce. Views expressed during research project. Sufficient for the purposes of reviewing the standard.
Disability	Do you have enough information to proceed?
	Significant knowledge in relation to needs of disabled adults using services and in relation to workforce. Views expressed during research project. Sufficient for the purposes of reviewing the standard.
Sex	Do you have enough information to proceed?
	Acknowledgement of legislation around this area. Views expressed during research project. Sufficient for the purposes of reviewing the standard.
Pregnancy	Do you have enough information to proceed?
	Acknowledgement of legislation around this area. Sufficient for the purposes of reviewing the standard.
Maternity	Do you have enough information to proceed?
	Acknowledgement of legislation around this area. Sufficient for the purposes of reviewing the standard.
Sexual orientation	Do you have enough information to proceed?
	Acknowledgement of legislation around this area. Views expressed during research project. Sufficient for the purposes of reviewing the standard.
Race	Do you have enough information to proceed?
	Acknowledgement of legislation around this area. Significant knowledge in relation to employer needs in relation to workforce ethnicity. Increasing knowledge in relation to service user needs by race. Views expressed during research project. Sufficient for the purposes of reviewing the standard.
Religion and Belief	Do you have enough information to proceed?

	Acknowledgement of legislation around this area. Increasing knowledge in relation to service user needs by religion and belief. Views expressed during research project. Sufficient for the purposes of reviewing the standard.
Gender reassignment	Do you have enough information to proceed?
	Acknowledgement of legislation around this area. Sufficient for the purposes of reviewing the standard.

4. What does the information you have tell you about how this standard might impact positively or negatively on the different groups within the target audience?

The core aim of the standard is to **improve the outcomes of people living with dementia and their carers through improving processes** in relation to health and care provision. In relation to diversity, equality and language, the introduction to the standard specifically states that:

“Good communication between health and social care professionals and people with dementia is essential. Treatment and care, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. People with dementia should have access to an interpreter or advocate if needed.”

For people living with dementia and their carers opinions varied as to whether the standard was inclusive and helpful for everyone. Key issues raised by this group included:

- To be more explicit within the standard about the need for inclusivity.
- The standard (esp. statement 9) reflects traditional family relationships that may not be the case for all. An example of the LGBT community was provided, where some reflection of the difference in support relationships amongst this community is required.
- The need to challenge the stereotype of dementia being an “old age disease” was strong sentiment expressed. The need to reflect the diversity of the people affected by dementia.
- Cultural considerations were highlighted as a factor, citing the stigma associated with having dementia in the Asian community making it difficult for people to access support through social care services. This was felt to be an issue for implementing the standard.

Workforce participants were asked to consider how inclusive the standard was of different people with dementia and their carers across various groups. Key issues raised were as follows:

- The underlying assumption evident in the standard that people with dementia were

part of a 'traditional' family and network of friends was raised. Reference was made to people with learning disabilities that may not be living in a traditional 'home' environment (potentially in care) when they develop dementia. As a result, they may not have had the same life experiences or relationships to fall back on as the standard suggests. This may mean that the only advocates they have are their paid carers, who may be best placed in this role in the absence of family and friends.

- Broader concerns over cultural norms in relation to recognising dementia, seeking help and accepting support in some communities was discussed. A sense that some communities do not access health, social care or voluntary sector support. As a result, there is an opportunity to be more proactive to encourage contact with these groups.
- Related to this was the need for cultural awareness amongst staff to be able to recognise the issues facing some members of the community.
- There was awareness that the implementation of the standard was key to having any impact on Equality, rather than how inclusive the document was.

5. Suggested changes to the standard to mitigate against uneven impacts.

Age	No
Disability	Yes
Sex	No
Pregnancy	No
Maternity	No
Sexual orientation	Yes
Race	Yes
Religion and Belief	Yes
Gender reassignment	Yes

In terms of support needed for people with dementia and their carers to use the standard the following issues were raised:

- Use existing community-based organisations to promote the standard. This applies to ethnic, religious and lifestyle groups.
- This was felt particularly beneficial for reaching the Asian community on two counts. Firstly, in terms of the availability of translation if required and secondly reflecting the need for trust to be established before introducing and expecting a response to the standard. As networks and relationships are pre-existing it was felt that working through these organisations would increase the response to the standard.

- There was also the suggestion of using some group work within communities to develop awareness and importantly understanding of the standard amongst groups.

In terms of improvements to mitigate against uneven impacts upon different groups within the community, workforce participants suggested the following:

- Support for the development of guidance associated with the standard that could consider how an individual statement related to various minority groups. Suggested examples included LGBT and learning disabilities.
- With regard to those who do not have access to the traditional family network, it was suggested that the word 'carer' needs more consideration. In particular, in relation to cases where it may have to include a paid employee as an advocate as they may be the one who mainly cares for them. It was felt necessary to reflect this in the standard and within any guidance produced.
- Some discussion around the importance of cultural and faith systems and how this might be reflected through the standard. One option suggested was to consider this in the context of the human rights agenda.
- The importance of monitoring data to ensure that the needs of different communities were being met and consider data from minority groups separately to ensure their voice is heard.
- The reference to people having a right to an interpreter or advocate may be unclear as to whether this was in relation to the condition or English not being the first language. It was felt this ambiguity should be addressed.

Suggestions from the workforce participants in relation to enhancements to support use of the standard by people with dementia, their carers and the workforce included:

- The need for ensuring people with dementia and their carers were aware of the standard and clear about expectations. However, there was some concern that people may be disappointed as raised expectations may not be met due to service cut backs.
- Some concern over the fact the standard was not compulsory and potential for it not to be taken seriously as a result.
- Guidance and training should be developed to raise awareness amongst practitioners, perhaps with examples of good practice and case studies. A feeling that this would bring the document to life. The 'Making it real' approach was cited as a positive way to develop these.
- Also, some suggestion that people who live with dementia could deliver training to staff to address some of the stereotypes and stigma associated with the condition.
- A view that the standard needed to sit within the broader context of government policy, alongside health and access issues.
- One interviewee did raise concern over the lack of a statement specifically for

carers, although there was recognition that this might be inappropriate in the context of this work.

6. Does the standard provide the opportunity to promote equality of opportunity or good relations by altering the standard or working with others?

Age	No
Disability	Yes
Sex	No
Pregnancy	No
Maternity	No
Sexual orientation	Yes
Race	Yes
Religion and Belief	Yes
Gender reassignment	Yes

The points raised under section 5 above raise a number of opportunities to promote equality through altering the standard.

7. Based on the work you have done - rate the level of relevance of the standard.

	Age	Disability	Sex	Pregnancy	Maternity	Sexual orientation	Religion and belief	Race	Gender reassignment
High									
Medium	✓	✓	✓	✓	✓	✓	✓	✓	✓
Low									
Unknown									

Guidance for categorisation:

High	<ul style="list-style-type: none"> ▪ There is substantial evidence that people from different groups or communities are (or could be) differently affected by the standard (positively or negatively) ▪ There is substantial public concern about the standard, or concerns have been raised about the standard's potential impact by relevant bodies ▪ The standard is relevant to all or part of the respective general duty, in the case of race, disability and gender.
Medium	<ul style="list-style-type: none"> ▪ There is some evidence that people from different groups or communities are (or could be) differently affected (positively or <u>negatively</u>). ▪ There is some public concern about the standard. ▪ The standard is relevant to parts of the respective general duty, although <i>all</i> of the protected characteristics are present among people affected by the standard.
Low	<ul style="list-style-type: none"> ▪ There is little or no evidence that some people from different groups or communities are (or could be) differently affected (positively or negatively). ▪ There is little or no evidence of public concern about

	<p>the standard.</p> <ul style="list-style-type: none"> The standard has little or no relevance to the respective general duty, in the case of race, disability and gender.
Unknown	<ul style="list-style-type: none"> No evidence or data has been collected therefore an assessment cannot be made

8. Is a further impact assessment required?

Age	No
Disability	No
Sex	No
Pregnancy	No
Maternity	No
Sexual orientation	No
Race	No
Religion and Belief	No
Gender reassignment	No

The suggestions raised in section 5 outline some enhancements that could be made to the standard and in particular in relation to any guidance and support provided alongside it. In the event that these are considered and at least in part implemented it is felt that there is no need for a further impact assessment. It may be more appropriate to conduct a review of progress on the points highlighted.

9. Please explain how you will monitor and evaluate this standard to measure progress?

Please explain how monitoring will be undertaken, when it will take place and who is responsible for undertaking it.

Full details of the quality measures, meanings and data sources are outlined within the standard itself.

10. EqIA Checklist

Confirm completion of the following steps:

Impact Assessment Steps 1-9	Yes	No
1. Defined the aims of your standard	✓	
2. Identified what we already know (i.e. what does the existing evidence base tell us?)	✓	
3. Identified what more we need to know (i.e. what gaps have we identified in our evidence base?)	✓	
4. Analysed the evidence (i.e. what does this all mean in relation to the standard?)	✓	
5. Considered any necessary changes & identified action (i.e. will you be taking action to make any changes? If yes, what, when and who? If not, what are your reasons for not taking any action?)	✓	
6. Identified opportunities to promote equality	✓	
7. Measured differential impact	✓	
8. Assessed whether further impact assessment work is needed	✓	
9. Outlined arrangements for monitoring & evaluation	✓	

Annex B: Workforce survey questionnaire

The National Institute for Health and Clinical Excellence (NICE) has asked Skills for Care (in partnership with Dementia UK), to field test the new quality standard on dementia care, Dementia – Supporting People to live well with Dementia.

The quality standard is intended to help people involved in dementia care focus on delivering the best possible outcomes for people who use services. We want to make sure that workers involved in dementia care have the chance to contribute to the quality standard, and would like to invite you to complete the survey below.

The survey should take no more than ten minutes to complete. It is completely anonymous, though you have the option of filling in your name to request further information. We may use quotes in the final report, but these will be anonymised so no-one can identify you. NICE will use your responses to help improve the draft quality standard before it is implemented.

If you would like a paper copy or copies of this questionnaire, or would like a copy in an accessible format such as

Braille, please contact Claire Dunn at Skills for Care on 0113 241 1231, or claire.dunn@skillsforcare.org.uk.

To answer the survey, you will want to read the full draft quality standard. Please click here to view it as a pdf or copy and paste the address into your browser

http://www.nice.org.uk/media/2A6/9B/Dementia_Draft_QS_for_consultation.pdf

1. To what extent do you agree or disagree that, taken as a whole, the standard in its current form will support high quality social care?

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- Not sure
- Not applicable

2. To what extent do the statements in the quality standard reflect or challenge current practice?

- These statements more or less reflect current practice
- These statements challenge current practice – a little
- These statements challenge current practice – a lot
- Not sure

3. For each statement, please tell us whether (a) you think it is clear (b) you would make any changes to it?

	Very clear	Quite clear	Not very clear	Not at all clear	Not sure
People living with dementia are supported to maintain relationships and have opportunities to contribute to the wider community.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia and their carers have choice and control in decisions affecting their care and support.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People in the early stages of dementia and their carers have opportunities to be involved in their palliative and end-of-life care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia have a care and plan based on individual needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia and their carers take part in a review of their care and support needs when their circumstances change and at least a year.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People who might have dementia are informed of benefits of attending a memory assessment and encouraged to do so.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia and their carers have opportunities to be involved in planning and evaluating services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia are supported to participate in activities based on individual interest and choice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia and their carers are supported to access independent advocacy services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia and their carers are in contact with a local adviser who provides information about dementia and how to access additional support.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia have their accommodation designed or adapted to meet their	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4. Do you think that the length of the standard is appropriate to encourage people in your job role to read and absorb the contents?

- Yes – around the right length
- No – too long
- No – too short
- Not sure

5. How do you think you will use the Quality Standard in practice? (Tick all that apply)

- Support and challenge care providers to deliver quality services
- Support and challenge staff to deliver quality services
- Reflective learning and supervision
- Reflect and improve on my own practice
- Work with service users to empower them to challenge services
- Work with carers to empower them to challenge services
- Impact measurement and performance management tool
- Demonstrate quality to CQC or commissioners
- Not sure
- Other (please specify)
- Other (please specify)

6. Do you feel that support will be required to assist practitioners in your setting implement the quality standard?

- Yes
- No
- Not sure
- Not applicable

7. If yes, what form should this take?

- Support from leaders and managers
- Publicity materials
- Awareness raising
- Training
- Other (please specify)

8. How should the Quality Standard be disseminated to dementia care professionals in your type of setting? (Tick all that apply)

- Communication to all employers
- Professional networks
- Trade press
- Unions
- Web promotion
- Hard copies distributed

- Other (please specify)

Thank you for completing the survey. Please answer some questions about yourself to help us ensure we have reached all parts of the dementia care community.

9. Gender: Please tick appropriate box?

- Male
- Female

10. Which age group best describes you?

- Under 18
- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 to 69
- Over 70

11. Please tick the box below which best describes the ethnic category to which you belong:

- White
- Mixed / Multiple ethnic group
- Asian / Asian British

- Black / African / Caribbean / Black British
- Other

12. What type of setting do you currently work in?

- Social care – local authority
- Social care – other public sector
- Social care – private sector
- Social care – voluntary/community sector
- Health sector
- Other (please specify)

13. What is your current job role?

- Frontline worker
- Manager/Supervisor
- Registered practitioner
- Commissioner
- Other (please specify)

If you would like more information or to get more involved with the field-testing of the dementia care standards, please give your name and contact details, and tick the appropriate boxes below.

14. About you

First name:

Last name:

Job title:

Organisation:

Email Address:

Phone Number:

15. Please tick if applicable

- I would like to receive a copy of the final report for the field testing
- I am interested in participating in a focus group as part of the field testing and give my permission to be contacted with more details
- I am interested in participating in an Equality Impact Assessment as part of the field testing and give my permission to be contacted with more details.

Annex C People affected by dementia – survey questionnaire

The National Institute for Clinical Excellence (NICE) is developing a new quality standard on supporting people to live well with dementia. The aim of the standard is to make sure that people with dementia and their carers receive high quality services

In August NICE published a draft of the standard and began to gather feedback. NICE has commissioned Dementia UK to ask people with dementia and their carers to comment on the standard. It is important that people with dementia and their carers have the chance to influence the standard.

So we would like you to complete the survey below:
The survey should take around 20 minutes to complete

It is completely anonymous, though you have the option of filling in your name to request further information

- If you don't wish to answer a question, please leave it blank and move on to the next one.
- We may use quotes in the final report, but these will be anonymous so no one can identify you.
- NICE will use your comments to help improve the quality standard before publishing the final version.

If you would prefer to fill in a paper copy of this questionnaire, please email Joy Watkins at Dementia UK at joy.watkins@dementiauk.org, or phone her on 020 7874 7209.

If you have any technical problems completing this survey please contact Claire Dunn at Skills for Care at claire.dunn@skillsforcare.org.uk, or phone her on 0113 2411231

On the next page you will be able to view a summary of the standard, which you will need to read before answering the questionnaire. If you would like to see the full text, please copy and

paste the address into your browser

http://www.nice.org.uk/media/2A6/9B/Dementia_Draft_QS_for_consultation.pdf

Please note this survey will close at midnight on 16th September 2012

Summary of the Quality Standard on Supporting People to Live Well with Dementia

The National Institute for Clinical Excellence (NICE) is developing a new quality standard for dementia care. The aim of the standard is to make sure that people with dementia and their carers receive high quality services.

What has happened so far?

NICE has published the draft standard which has 13 statements. They have commissioned Dementia UK to ask people with dementia and their carers to give comments which they will use to revise the Standard before it is published.

How will the quality standard be used?

The standard will be used to improve the lives of people with dementia and their carers.

- People living with dementia and their families will know what to expect and be confident to asking for the support they need.
- Local authorities and others who commission services will be able to set up services that meet people's needs.
- Organisations who provide care and support will know how to run their services effectively.
- People in care jobs (e.g. social workers and care staff) will know how they should be working

Things to think about before you answer the survey questions

In your own experience:

- Can you see any problems with wording of the statement?
- Is the statement too vague How could it be tightened up?
- Does this describe high quality care, as opposed to minimum standards?
- If this statement was in use, would it help you get what you need?
- Would the statement help everyone? Or would it help some people with dementia more than others?

What does the draft quality standard say?

Below are the statements that have been drafted for us to comment on.

No. Draft quality statements

1. People who are concerned that they or someone they know may have dementia are listened to and have opportunities to discuss such concerns.
2. People who might have dementia are informed of the benefits of attending a memory assessment service and encouraged to do so.
3. People living with dementia and their carers are in contact with a local adviser who provides information about dementia and how to access additional support.
4. People living with dementia and their carers have choice and control in decisions affecting their care and support.
5. People living with dementia have a care and support plan based on individual needs.
6. People living with dementia and their carers take part in a review of their care and support needs when their circumstances change and at least once a year.
7. People in the early stages of dementia and their carers have opportunities to be involved in planning their palliative and end-of-life care.
8. People living with dementia are supported to participate in activities based on individual interest and choice.
9. People living with dementia are supported to maintain relationships and have opportunities to contribute to the wider community.
10. People living with dementia are supported to access services that help maintain their physical and mental wellbeing.
11. People living with dementia have their accommodation designed or adapted to meet their specific needs.
12. People living with dementia and their carers have opportunities to be involved in planning and evaluating services
13. People living with dementia and their carers are supported to access independent advocacy services.

1. For each statement, please tell us whether (a) you think it is clear (b) you would make any changes to it?

	Very clear	Quite clear	Not very clear	Not at all clear	Not sure
People living with dementia are supported to maintain relationships and have opportunities to contribute to the wider community.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia and their carers have choice and control in decisions affecting their care and support.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People in the early stages of dementia and their carers have opportunities to be involved in their palliative and end-of-life care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia have a care and plan based on individual needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia and their carers take part in a review of their care and support needs when their circumstances change and at least a year.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People who might have dementia are informed of benefits of attending a memory assessment and encouraged to do so.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia and their carers have opportunities to be involved in planning and evaluating services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia are supported to participate in activities based on individual interest and choice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia and their carers are supported to access independent advocacy services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia and their carers are in contact with a local adviser who provides information about dementia and how to access additional support.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia have their accommodation designed or adapted to meet their specific needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People who are concerned that they or someone know may have dementia are listened to and have opportunities to discuss such concerns.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with dementia are supported to services that help maintain their physical and wellbeing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Would you make any changes to any of the statements? If so, what?

2. Would people with dementia have a better life if this standard was met? (please tick one)

- It would make no difference
- It would improve life for people with dementia – a little
- It would improve life for people with dementia – a lot
- It would make life worse
- Not sure

3. Would you be able to use the standard to make life better? (Tick all the boxes that you agree with)

- I would understand better what support I should expect to receive
- I would understand how staff should be working to support me
- I would feel more confident to ask for what I need
- I would be able to express concern if my care did not meet the standard
- I could represent other people with dementia and carers in improving services
- Not sure

Other (please specify)

***4. Do you feel people with dementia and their carers will need support to use this standard? (please tick one)**

- Yes
- No
- Not sure

5. If you answered yes to the previous question. Do you feel people with dementia and their carers will need support to use this standard? (Tick all the boxes that you agree with)

- Support from social services
- Support from organisations who represent people with dementia and carers
- Support from an advocate or individual support worker
- Publicity materials
- Awareness raising
- Other (please specify)

Please answer some questions about yourself to help us ensure we have reached all parts of the dementia care community. Please tick one option in each of the following questions.

6. Gender: Please tick appropriate box?

- Male
- Female
- Prefer not to say

7. Please tell us which category you fit into?

- I am a person with dementia
- I am caring for a person with dementia
- I am a former carer of a person with dementia
- I both care/ have cared for someone with dementia and also have dementia myself

8. Do you live...

- Alone
- With spouse or partner
- With other family members
- In residential care
- Other (please specify)

9. How long ago were you diagnosed with dementia?

- Less than 2 years ago
- 2-5 years ago
- More than 5 years ago

10. Which age group best describes you?

- Under 18
- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 to 69
- Over 70
- Prefer not to say

11. Do you suffer from any disabilities or serious conditions other than dementia?

- Yes
- No
- Prefer not to say

12. Please tick the box below which best describes the ethnic category to which you belong:

- White
- Mixed / Multiple ethnic group
- Asian / Asian British
- Black / African / Caribbean / Black British
- Other

This section is optional

If you would like more information or to get more involved with the field-testing of the dementia care standards, please give your name and contact details, and tick the appropriate boxes below.

In line with the Data Protection Act 1998 Dementia UK and our partners Skills for Care will not contact you without your permission or share your details with any other party without your consent.

13. About you

First name:	
Last name:	
Job title:	
Organisation:	
Email Address:	
Phone Number:	

14. Please tick if applicable

- I would like to receive a copy of the final report on the project

- I am interested in participating in an Equality Impact Assessment as part of the project and give my permission to be contacted with more details. This will involve spending a few hours discussing with other people the effect the standard will have on different groups of people with dementia (e.g. people from different cultures).

Annex D: Workforce focus group invite to participate

[Date]

Dear [Firstname]

Field testing of the pilot social care quality standard on the care of people with dementia, Dementia – Supporting People to live well with Dementia

You are invited to contribute to one of the most exciting challenges in policy making for social care. The National Institute for Health and Clinical Excellence (NICE) has an international reputation as a developer of professional guidance for the NHS and public health in England and Wales. NICE also develops a range of evidence-based resources including quality standards.

As part of the Government's reforms of health and social care, NICE has been given a new responsibility for developing guidance and quality standards for the social care sector. NICE will be using its experience and knowledge of guidance and standards and applying this to social care to help those working in this area to drive up quality.

NICE quality standards will describe what high-quality social care in England should include. This fieldwork is a unique opportunity for you to inform the development and delivery of these quality standards. The quality standard 'Dementia – supporting people to live well with dementia' is comprised of 13 concise, measurable statements that describe high-quality care for this area. Your insight will help us ensure that these statements are useful, measurable and will make a difference to the quality of care for people living with dementia and their carers.

Skills for Care (in partnership with Dementia UK) is undertaking the field-testing on behalf of NICE. We would like to invite you to a focus group being held at:

[LOCATION] on [DATE/TIME]

The focus group will involve 8-12 social care workers involved in dementia care, [who work at [INSERT CARE HOME NAME]/ drawn from across the sector.] At the focus group, we will ask you about your views of the standard, how you might use it in everyday practice to drive

up quality, and the practical issues that you might face in implementing the quality standard in your workplace.

We have enclosed a Participant Information Sheet with this letter which sets out the detail of this research project in more detail. Also enclosed with this letter is a Consent Form, which we will ask you to complete on the day (you do not have to bring it with you as we will have spare copies).

If you have any immediate questions about the research please do not hesitate to contact me. Please reply to Claire Dunn at claire.dunn@skillsforcare.org.uk to confirm your attendance, and please let us know if you have any accessibility requirements.

Yours sincerely

Paul Buchanan
Programme Head – Research and Evaluation
Skills for Care

Enc. Participant Information Sheet
Consent Form

Dementia care quality standard: Dementia – Supporting People to live well with Dementia:
Draft for consultation 16/08/12

Annex E – Workforce Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Project title: Field testing of the pilot social care quality standard on the care of people with dementia, *Dementia – Supporting People to live well with Dementia*

Focus group event

[LOCATION/DATE/Start-End time]

This project is being undertaken by:



Skills for Care
West Gate
6 Grace Street
Leeds
LS1 2RP
www.skillsforcare.org.uk

On behalf of:



**National Institute for
Health and Clinical Excellence**

National Institute for Health and Clinical
Excellence
MidCity Place
71 High Holborn
London
WC1V 6NA
www.nice.org.uk

Contact details:

Claire Dunn, Project Officer
Tel: 0113 241 1231
Email: claire.dunn@skillsforcare.org.uk

We would like to invite you to contribute to the field testing of this important new quality standard. Before you decide whether to be involved you should read the information in this document.

Below are the answers to some of the questions that you might have about the field testing, the people involved in it and what it will involve for you.

If after reading this document you still have unanswered questions then please feel free to contact us, or discuss them at the focus group.

What is the purpose of the field testing?

The main purpose of the field testing is to assess the relevance, usefulness, acceptability, clarity and potential impact of the social care quality standard. We will send you a copy of the quality standard before you come to the group.

The key questions to be addressed are:

- How relevant to high quality social care are the selected areas within the quality standard?
- How acceptable are the statements and associated measures and the clarity of the wording used?
- Are there any areas covered by the quality standard which may impact unevenly on different groups of people with dementia and/or carers (for example, in terms of age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex and sexual orientation)
- If there are areas covered by the quality standard which may impact unevenly on different groups of people with dementia and/or carers can delivery of the care described by the quality standard be adapted so as to reduce inEquality
- What factors, for example the content and format of the quality standard, could either help or hinder the effective use of the quality standard?
- In what ways do participants in the field testing envisage the quality standard being used?
- What support, if any, is needed to help stakeholders (including providers, commissioners and people with dementia, their families and carers (paid and unpaid), and organisations representing their interests) use the quality standard?
- To what extent do the quality standards reflect or challenge current practice?
- Do participants in the field testing have suggestions for effective ways of communicating the quality standard when it is published?

Skills for Care (in partnership with Dementia UK) has been asked to undertake the field testing by the National Institute for Health and Clinical Excellence (NICE), who are responsible for producing the standard. Skills for Care is leading on consultation with the dementia care workforce, while Dementia UK is leading on consultation with people with dementia and carers.

Who is Skills for Care?

Skills for Care is an employer-led organisation working to ensure that the adult social care workforce has the attitudes, values, skills and qualifications necessary to deliver high quality social care. You can find out more about Skills for Care at www.skillsforcare.org.uk.

Who is NICE?

The National Institute for Health and Clinical Excellence (NICE) develops national guidance on the promotion of good health and the prevention and treatment of ill-health. NICE is also responsible for developing quality standards from best available evidence that span care pathways for a range of settings and conditions. Details of our work programmes and examples of guidance and quality standards produced can be found on the NICE website (www.nice.org.uk).

The NICE Quality Standards Programme was established in 2009 to manage the development of quality standards for healthcare. Further information about NICE quality standards is available on the [NICE website](#). In 2011, NICE was also asked by the Department of Health to pilot the development of two quality standards for social care. The interim process for developing pilot social care quality standards can be found on the [NICE website](#). Further information about the social care programme of work can be found on the [NICE website](#).

Can I trust you?

Skills for Care acts in accordance with the Market Research Society's Code of Conduct and the Data Protection Act 1998 at all times. Researchers are fully trained, and are experienced in implementing safeguarding and disclosure procedures.

We will ensure that the purpose of the focus group is clearly explained to you. You have the right to leave at any point. Should you wish not to complete the focus group, we will use the answers you had earlier given unless you request otherwise. Attending the focus group is completely voluntary.

All the information that you provide will be treated in the strictest confidence* and will be used for research purposes only. If you give us permission to, we will use quotes in the final report, but will anonymise these so you are not identified. Your identity and personal details will not be shared with NICE and you will not be identified in any research reports produced.

**except in circumstances where it is believed that you or others might be at risk of harm, or where you disclose that the law is being broken, in which case we have a duty to report our concerns to the relevant authority/ies (i.e. the local safeguarding board or the local authority lead). We would discuss this with you before taking any action.*

The focus group will be recorded if all participants give permission, and the information will be stored on our secure file servers. Personal records, recordings of interviews and so on are saved using anonymous filenames and any identifying information, including names, references to places or other information that could identify you as a participant are removed from the records.

Why have I been asked to participate?

Your work may sometimes or often involve the care of people with dementia. We want to know about how workers might use the new quality standard to help inform their practice.

Skills for Care and Dementia UK will be running:

- 3 focus groups with 8-12 social care workers, across England
- an online survey available to all social care workers, people with dementia and carers (paper copies available on request)
- 3 focus groups and 10 interviews with people with dementia and their carers
- 6 interviews with representative bodies.

If you would like to fill in the online survey in addition to, or instead of, attending a focus group, please go to [INSERT LINK]. To request a paper copy please contact Claire Dunn on [INSERT NUMBER].

Questions and next steps

To confirm your attendance, if you have any questions about the research, or if you require support to participate (for example a Loop system, a British Sign Language translator or mobility support) please contact Claire Dunn on 0113 241 1231 or e-mail claire.dunn@skillsforcare.org.uk.

Should you need to contact someone with *a complaint about the way the research is conducted*, please contact Paul Buchanan, Programme Head – Research and Evaluation, Skills for Care on 01236 421 372. Paul is the Independent Complaints Officer for this project.

Please note that you will have the opportunity to request a copy of the research findings when you consent to taking part in this research.

Thank you for taking the time to read this information sheet. Please do not hesitate to contact us if you have any questions.

We look forward to seeing you at **LOCATION, DATE/TIME!**

Annex F: Workforce focus group script

Introduction – purpose of day, intro to field-testing, NICE and Skills for Care. Collect consent forms and check permission to record. (10 mins)

Warm-up exercise (10 mins)

Turn to the person next to you and introduce yourself. Tell each other

- (a) Your first name
- (b) What your work with people with dementia involves.

Then introduce your partner to the whole group.

Has everyone read the new Quality Standard? (Circulated before the day).

1. Let's look at statements [1-5/6-9/10-13] (change for each group). Do you feel you understand these – is the meaning clear? Is there anything you would improve or add? (20 mins)
2. How do you think you will use the document to help drive up quality in your setting? (20 mins)
3. What issues do you think you might encounter in implementing these standards in your everyday practice? How would you work through these issues? (20 mins)
4. To what extent do you feel this new standard challenges existing practice and could help improve service user outcomes? (20 mins)
5. What would support or encourage social care workers like you to be aware of and use these standards? (15 mins)

Any final comments/questions / Thanks to all for their contribution and explanation of what will happen with the research. (5 mins)

Total: 120 mins.

Annex G: Workforce interview script

Field testing of the pilot social care quality standard on the care of people with dementia, *Dementia – Supporting People to live well with Dementia*

Interview guide for workforce

The standard is made up of 13 statements along with what these mean in practice for practitioners, including you as health and social care workers (the descriptors)

We have selected a few statements that are pertinent to your work and then will ask for your comments on the standard as a whole.

Looking at each of the selected statements (with accompanying description for social and health care workers) please respond to question one below (ask for someone to write notes on each poster) :

So for statement xx

1. Do you feel you understand the statement / descriptor? Is its meaning clear? Is there anything you would improve or add?
2. What does the statement mean for you and your practice?

Looking at the whole of the standard

3. What issues do you think you might encounter in implementing this standard in your everyday practice? How would you work through these issues?
4. To what extent do you feel this new standard challenges existing practice and could help improve service user outcomes?
5. How do you think you could use the standards to help drive up quality in your setting?
6. What would support or encourage social care workers like you to be aware of and use the standard.
7. Any other comments or questions

Annex H: People affected by dementia – invite to participate



(Date)

Dear

I am writing to invite you to help with a new project to test the quality standard on dementia care, Dementia – Supporting People to live well with Dementia. We are holding a focus group for family carers at our office in London on (dates). Having looked at our membership, we feel that you would be an ideal person to take part.

The National Institute for Clinical Excellence (NICE) has commissioned Dementia UK (in partnership with Skills for Care) to test the new quality standard on dementia care. I am including a summary of the draft standard with this letter.

The standard describes what a high quality social care service for people with dementia and their carers should be like. It will also give information on how we can measure whether or not the standard is being met.

It is important that people with dementia and their carers have opportunities to comment on the standard as it is being developed. Dementia UK is helping with this process of involving people with dementia and their carers.

NICE will consider carefully all the comments received from the focus group. This gives project will give people with dementia and their carers the opportunity to influence, at a high level, **the quality of services that families receive**.

Would you be willing to join a discussion group for this research project?

The focus group will involve 8 family carers of someone with dementia and take up to an hour and a half. We will give you a £20 gift voucher and pay your expenses.

We have enclosed a;

- *Participant Information Sheet*. This gives details of the project.
- *Consent Form*. We will ask you to complete this on the day (you do not have to bring it with you as we will have spare copies).

Please reply to Julia Burton-Jones, jburtonjo@aol.com, to say you are happy to take part. Let her know if you are free on the dates suggested. Please ask her any questions about this research project.

We are working to a tight deadline and would be grateful if you would respond as soon as possible to this request.

Warmest wishes,

Joy Watkins
Development Lead, Uniting Carers
Dementia UK

Annex I: People affected by dementia – Participant Information Sheet

Project Information Sheet

Testing of the pilot quality standard for dementia care, *Dementia – Supporting People to live well with Dementia*

Focus group event

(Location/Date/Start- End Time)

This project is being undertaken by:



Dementia UK
6 Camden High Street
London
NW1 0JH
T 020 7874 7200
F 020 7874 7219
info@dementiauk.org
www.dementiauk.org

On behalf of:



**National Institute for
Health and Clinical Excellence**
National Institute for Health and Clinical
Excellence
MidCity Place
71 High Holborn
London
WC1V 6NA
<http://www.nice.org.uk/>

Contact details:

Julia Burton-Jones

Dementia Pioneer
Dementia UK
6 Camden High Street
London NW1 0JH

Telephone: 01634 813366

Email: jbartonjo@aol.com

Dementia care quality standards field testing

Your comments on the draft quality standard for dementia care

We would like to invite you to contribute to discussions about this important new quality standard for dementia care.

Before you decide whether to be involved, please read the information below. This answers any questions you might have about the project.

If after reading this document you still have unanswered questions then please feel free to contact us, or discuss them at the focus group.

What is the quality standard for dementia care?

The National Institute for Clinical Excellence (NICE) is developing a new quality standard for dementia care.

The aims of the standard are:

- that support services for people with dementia are consistent across the country
- that services are of a high quality.

The standard will help people with dementia and their carers know what to expect from services. It will also help those who provide services to be clear about how best to support people affected by dementia.

What is the purpose of this project?

It is important that people with dementia and their carers can comment on the standard as it is being developed. Your personal experience helps you to comment on whether the standard is useful.

- Will it make a difference to the lives of people with dementia and their carers?
- Could it be improved in ways that will make it easier to use?
- Will people with dementia need support to use the standard to improve care?

Dementia UK is supporting this to happen. We are working with Skills for Care who will be testing the standard with people in paid care roles.

Who is NICE?

The National Institute for Health and Clinical Excellence (NICE) develops national guidance on health. It also develops quality standards based on research about health problems. You can find out more about the work of NICE at their website (www.nice.org).

Can I trust you?

- Dementia UK promises to explain the purpose of the focus group to you.
- You can leave at any point. We will only use answers you have given if you are happy for us to do so.
- All the information you provide will be treated in strictest confidence. It will only be used for the purposes of the research project.
- If you give us permission, we will use quotes in the final report. But these will be anonymous so you cannot be identified.
- Your identity and personal details will not be shared with NICE. You will not be identified in any research reports produced.
- The focus group will be tape recorded if all participants give permission. Information will be stored on the secure file servers of our partner in the research, Skills for Care. They will remove any references that could identify you.

Why have I been asked to take part?

Dementia UK is looking for a range of participants to reflect different situations. We feel your experiences put you in an ideal position to comment on behalf of people with dementia and their carers as part of a focus group.

How do I find out more?

To take part in the focus group, or if you have any questions, please contact

Julia Burton-Jones, Dementia UK

Telephone: 01634 813366

Email: jburlonjo@aol.com

To make a complaint about the way the research is carried out, please contact

Joy Watkins, Development Lead, Uniting Carers Dementia UK

Telephone 020 7874 7209,

Email: Joy.Watkins@dementiauk.org.

Thank you for taking the time to read this information sheet. We look forward to hearing from you.

Annex J: Summary of the standard for people affected by dementia



Summary of the Quality Standard on Supporting People to Live Well with Dementia

The National Institute for Clinical Excellence (**NICE**) is developing a new quality standard for dementia care. The aim of the standard is to make sure that people with dementia and their carers receive high quality services.

What has happened so far?

NICE asked a group of experts in dementia to agree a list of statements they think should be in the standard. Later in this information sheet you will see the **13 statements** they have drafted.

In August NICE published this draft standard with its 13 statements and began to gather feedback. NICE has commissioned Dementia UK to ask people with dementia and their carers to **give comments**. We will be asking each person we approach to comment on just 4 of the statements, so that we can look at in detail at how they would all work in practice. Other groups will be asked for their views too, including people who work in dementia care.

At the end of the consultation, the statements will be **revised** by NICE and a new quality standard will be published.

How will the quality standard be used?

The quality standard will be used to make real improvements to the lives of people with dementia and their carers.

- People living with dementia and their families will know **what to expect** and will have confidence to ask for the support they need.
- Local authorities and others who **commission** services will know where to invest their money. They will be better able to set up services that meet people's needs.
- Organisations who provide care and support will know how to run their **services** so that they are effective.

- People in care jobs (e.g. social workers and care staff) will know how they should be **working to support** people with dementia and their carers.

What happens now?

We will be asking you to look at 4 of the 13 quality statements on the next page and tell us how useful they are. To find out which 4 statements we want you to look at, read the information we have sent with this summary. For each statement we give you ask yourself:

- Could it be used to make care better?
- Could you improve the wording?

What does the draft quality standard say?

Below are the statements that have been drafted for us to comment on.

No.	Draft quality statements
1	People who are concerned that they or someone they know may have dementia are listened to and have opportunities to discuss such concerns.
2	People who might have dementia are informed of the benefits of attending a memory assessment service and encouraged to do so.
3	People living with dementia and their carers are in contact with a local adviser who provides information about dementia and how to access additional support.
4	People living with dementia and their carers have choice and control in decisions affecting their care and support.
5	People living with dementia have a care and support plan based on individual needs.
6	People living with dementia and their carers take part in a review of their care and support needs when their circumstances change and at least once a year.
7	People in the early stages of dementia and their carers have opportunities to be involved in planning their palliative and end-of-life care.

8	People living with dementia are supported to participate in activities based on individual interest and choice.
9	People living with dementia are supported to maintain relationships and have opportunities to contribute to the wider community.
10	People living with dementia are supported to access services that help maintain their physical and mental wellbeing.
11	People living with dementia have their accommodation designed or adapted to meet their specific needs.
12	People living with dementia and their carers have opportunities to be involved in planning and evaluating services
13	People living with dementia and their carers are supported to access independent advocacy services.

Things to think about

NICE want us to be practical in giving feedback. The quality standard will not be worthwhile unless it can be used to make a difference. Think about how the statements might be used in the real world. You can relate them to your own experiences to help us understand how useful they are.

For each statement we need to consider:

- Can you see any **problems** with the way the statement is worded? Perhaps it is not clear what is meant, or you could interpret it in different ways.
- Will this statement help people providing support understand what they need to do? Is it **specific** enough for people to see where and how they could make changes? If you think it is too vague or general, can you suggest ways of tightening it up?
- Does this statement describe high quality care, as opposed to minimum standards? It needs to paint a picture of an **improved situation**, not just describe what is already happening.

- If this statement was in use, would it help (or would it have helped) you get **what you need**?
- Would you be able to **measure** if the standard had been met? How would you know if the statement was true?
- Would the statement help **everyone**? Or would it help some people with dementia more than others? It is important to consider people with different experiences, like people who are diagnosed younger.

A word about the where the standard will be used

This standard is mainly for **social care** settings. (There is another standard that deals mainly with healthcare issues). It will be used mainly to influence the kind of services that are provided by and through local authorities. It might be helpful when you are reading the statements to think about the kind of help that would come through your local social services or organisations in your area that work with people with dementia. This standard will inform the care and support people with dementia receive in their own homes, and also in places like day centres and care homes.

You can look at the full draft standard (34 pages) on the website of NICE at <http://www.nice.org.uk/qualitystandards/socialcare/careofpeoplewithdementiaconsultation.jsp>.

Annex K: People affected by dementia - focus group script

Introduction – purpose of day, intro to project, NICE and Dementia UK & Innovations in Dementia. Collect consent forms and check permission to record. Read agreed script about the purpose of the day and the need to stay focussed on the statements – explanation that time will not allow detailed descriptions of individual experiences. (JBJ to draft)
(10 mins)

Warm-up exercise, if group members do not know each other (10 mins)

Turn to the person next to you and introduce yourself. Tell each other

- (a) Your first name
- (b) Something interesting about you

Then introduce your partner to the whole group.

Has everyone read the new Quality Standard? (Circulated before the day).

Let's look at statements (see lists below), one at a time. (15 minutes per statement – each statement on a separate card given to participants before it is discussed)

1. What do you think this statement means?
2. Will this statement help people providing support understand what they need to do?
3. If this statement was in use, would it help (or would it have helped) you get what you need?
4. Would you make any changes to the way the statement is worded?

Any final comments/questions / Thanks to all for their contribution and explanation of what will happen with the research. (5 – 10 mins)

Total: 90 mins.

Statements to look at with each focus group:

People with dementia

- (4) People living with dementia and their carers have choice and control in decisions affecting their care and support.
- (3) People living with dementia and their carers are in contact with a local adviser who provides information about dementia and how to access additional support. (may be linked with discussion of 4)
- (5) People living with dementia have a care and support plan based on individual needs. (may be linked with discussion of 4)
- (8) People living with dementia are supported to participate in activities based on individual interest and choice.
- (9) People living with dementia are supported to maintain relationships and have opportunities to contribute to the wider community.
- (12) People living with dementia and their carers have opportunities to be involved in planning and evaluating services

People with dementia and carers

- (2) People who might have dementia are informed of the benefits of attending a memory assessment service and encouraged to do so.
- (6) People living with dementia and their carers take part in a review of their care and support needs when their circumstances change and at least once a year.
- (7) People in the early stages of dementia and their carers have opportunities to be involved in planning their palliative and end-of-life care.
- (11) People living with dementia have their accommodation designed or adapted to meet their specific needs.
- (13) People living with dementia and their carers are supported to access independent advocacy services.

Carers

- (1) People who are concerned that they or someone they know may have dementia are listened to and have opportunities to discuss such concerns.
- (3) People living with dementia and their carers are in contact with a local adviser who provides information about dementia and how to access additional support.
- (5) People living with dementia have a care and support plan based on individual needs.
- (6) People living with dementia and their carers take part in a review of their care and support needs when their circumstances change and at least once a year.
- (7) People in the early stages of dementia and their carers have opportunities to be involved in planning their palliative and end-of-life care.
- (10) People living with dementia are supported to access services that help maintain their physical and mental wellbeing.

Annex L: People affected by dementia – interview script

Testing of the Quality Standard on Supporting People to Live Well with Dementia

Topic guide – interviews with carers and people with dementia

(Please check) Have you read the summary of the quality standard sent to you in advance? (ensure read prior to interview and re-arrange if necessary). *For each question, explain and rephrase if not understood initially by interviewee.*

General questions about the standard

1. Do you agree or disagree that the standard as a whole will lead to high quality care for people with dementia and their carers? (*Probe for reasons behind answer*)
2. If this standard is adopted, will it lead to better services? Or does it just reflect how things are at the moment? (*Probe for reasons behind answer*)

Specific questions asked for each statement discussed

3. Can you see what statement x means?
4. Could statement x be used to improve the lives of people with dementia and their carers?
5. Would it be possible to measure if the statement had been met?
6. Would you make any changes to statement x?

General questions about the standard

7. Is the standard helpful for different groups of people with dementia and carers, for example people from other cultures or people diagnosed at a young age? Or would it miss out people whose situations are unusual?
8. Would people with dementia and their carers need support to use the standard? If so, what support would they need?
9. Is there anything else you would like to say about the standard?

If you would like more information, or to get more involved with this project, please let me check your contact details.

First name:

Last name:

Email address:

Telephone number:

- I would like to receive a copy of the final report of the project
- I am interested in participating in an Equality Impact Assessment as part of the project and give my permission to be contacted with more details. (explain the purpose of the EIA to interviewee using script from SfC)

Annex M: Representative bodies interview script

(Please check) Have you read the new Quality Standard? (Circulated before the day)

1. To what extent do you agree or disagree that, taken as a whole, the standards in their current form will support high quality social care?
2. To what extent do the quality standards reflect or challenge current practice?
3. To what extent do you think the statements are clear and easy to understand?
4. Are there any changes you would make?
5. Is there anything missing from the statements?
6. How effective do you think the suggested measures will be as an indicator of progress?
7. How inclusive are the standards of the needs of different groups of people with dementia and carers, for example minority groups and the seldom heard?
8. How could the standards be improved to mitigate against any uneven impacts felt by the different groups?
9. What could support use of the quality standard among people with dementia and carers/workforce [delete as apt depending on whether the interviewee represents the former or latter group]?
10. What challenges might be encountered?
11. How could these be overcome?
12. How will your organisation use the standards?
13. How should the standards be disseminated?

If you would like more information or to get more involved with the field-testing of the dementia care standards, please let me check your contact details.

First name:

Last name:

Job title:

Organisation:

Email address:

Telephone number:

- I would like to receive a copy of the final report for the field testing
- I am interested in participating in an Equality Impact Assessment as part of the field testing and give my permission to be contacted with more details.

Annex N: Participant Profiles

Profile of survey respondents

Workforce survey

The table below shows the sectoral characteristics of respondents to the workforce survey, compared to the NMDS-SC data on all social care establishments that provide care for people with dementia in England. (The survey was open to all in the UK so it should be noted that this is an imperfect comparison group, however it is useful for the purposes of illustration). It shows that the survey sample is broadly representative of the dementia social care workforce, with the majority of workers concentrated in the private sector. The survey sample also included 17 workers who are employed in the health sector.

Sector	Sample			NMDS-SC
	Response	Frequency	% total sample (including health)	
Base		83	100%	65
Social care – local authority		14	17%	22%
Social care – other public sector		3	4%	5%
Social care – private sector		36	43%	55%
Social care – voluntary/community sector		12	15%	18%
Health sector		17	21%	*
Other		1	1%	*
No response		17	*	*
				All social care establishments providing care for people with dementia in England
				10,161
				30%
				3%
				58%
				9%
				*
				*
				*

The table below shows the job roles of respondents to the workforce survey, mapped to similar job roles within the NMDS-SC data on all social care establishments that provide care for people with dementia in England. The sample suggests an over-representation from managers and supervisors in the social care sector, with fewer frontline workers. This is in line with the aspirations of the study, which sought to ensure that managers in particular would respond, since they will play a key role in implementing the standard.

Job Role		Sample		NMDS-SC
Response	Frequency	% total	% social care, exc. commissioners	All social care establishments providing care for people with dementia in England
Base	87	100%	61	353,292
Manager/Supervisor	45	52%	62%	7%
Registered practitioner [/Professional]	9	10%	8%	6%
Frontline worker [/Direct care]	9	10%	3%	73%
Other	21	24%	26%	14%
Commissioner	3	3%	*	
No response	13	*	*	

The table below shows the gender characteristics of respondents to the workforce survey. In the social care sector in England, 86% of the workforce are female and 14% male (NMDS-SC data), so the sample is slightly less representative of the male workforce than would be ideal.

Gender	Frequency	%
Base	91	100.0%
Male	5	5.5%
Female	86	94.5%
No response	9	*

The table below shows the age characteristics of respondents to the workforce survey. This is broadly representative of the workforce as a whole. In social care in England, the mean age of a dementia care worker is 42.6.

Age Group	Frequency	%
Base	91	100.0%
Under 18	0	0.0%
18 to 24	1	1.1%
25 to 34	6	6.6%
35 to 44	17	18.7%
45 to 54	45	49.5%
55 to 64	16	17.6%
65 to 69	4	4.4%
Over 70	2	2.2%
No response	9	*

The table below shows the ethnic group of respondents to the workforce survey. The survey sample appears to slightly under-represent non-White workers, based on a comparison with the social care workforce in England. However, the survey was open to UK wide workers which may explain the discrepancy. (NMDS-SC data suggests that 76% of staff employed in dementia social care in England are white, 18% black or other ethnic minority (six percent unknown ethnicity))

Ethnic Group	Frequency	%
Base	91	100.0%
White	81	89.0%
Mixed / Multiple ethnic group	2	2.2%
Asian / Asian British	4	4.4%
Black / African / Caribbean / Black British	3	3.3%
Other	1	1.1%
No response	9	*

Given the problems in choosing an appropriate comparison group, and the relatively small sample size, we decided not to weight the sample data but have reported throughout this report where there are apparent differences reported by groups of respondents.

People affected by dementia

The majority of respondents to the survey were carers.

Respondent Status	Frequency	%
Base	103	100.0%
I am a person with dementia	6	5.8%
I am either a carer or former carer for a person with dementia	97	94.2%
I both care/ have cared for someone with dementia and also have dementia myself	0	0.0%
No response	10	*

Home Status	Frequency	%
Base	103	100.0%
Not Applicable	97	94.2%
Alone	3	2.9%
With spouse or partner	2	1.9%
With other family members	0	0.0%
In residential care	1	1.0%
No response	10	*

Time Since Dementia Diagnosis	Frequency	%
Base	103	100.0%
Not Applicable	97	94.2%
Less than 2 years ago	2	1.9%
2-5 years ago	2	1.9%
More than 5 years ago	2	1.9%
No response	10	*

Gender	Frequency	%
Base	105	100.0%
Male	23	21.9%
Female	81	77.1%
Prefer not to say	1	1.0%
No response	8	*

Age Group	Frequency	%
Base	103	100.0%
Under 18	0	0.0%
18 to 24	0	0.0%
25 to 34	3	2.9%
35 to 44	7	6.8%
45 to 54	18	17.5%
55 to 64	30	29.1%
65 to 69	21	20.4%
Over 70	23	22.3%
Prefer not to say	1	1.0%
No response	10	*

Ethnicity	Frequency	%
Base	100	100.0%
White	94	94.0%
Mixed / Multiple ethnic group	3	3.0%
Asian / Asian British	0	0.0%
Black / African / Caribbean / Black British	0	0.0%
Other	3	3.0%
No response	13	*

Disability Status	Frequency	%
Base	98	100.0%
Disabled	27	27.6%
Non-Disabled	64	65.3%
Prefer not to say	7	7.1%
No response	15	*

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