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

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Executive summary

Background and context

Dementia is one of the most important issues facing England as the population ages. There are estimated to be over 800,000 people in the UK with dementia and numbers are expected to double in the next thirty years.¹

In 2011, NICE took responsibility for developing quality standards for social care. In light of this new role, a decision was taken to revisit the existing NICE Quality Standard for Dementia and produce a new pilot standard encompassing the whole dementia care workforce, with a particular targeting of social care commissioners and providers.

The quality standard is intended to help the social care sector focus on delivering the best possible outcomes for people who use services. It is also intended to help people living with dementia, and their families and carers, understand what services they should expect from their care provider.

The field testing

The main purpose of the field testing was to assess the *relevance, usefulness, acceptability, clarity* and *potential impact* of the social care quality standard, through taking the standards out to people who have dementia, their carers, commissioners and practitioners working in the dementia field.

The field testing was undertaken on behalf of NICE by Skills for Care with Dementia UK. It involved a mixed methods approach involving individual interviews, focus group events, and an online/paper survey. In total, 124 social care workers, managers and commissioners; 125 carers, 18 people with dementia and six representative bodies contributed to the field testing.

Findings

- The vast majority of participants felt that the standard **will support high quality social care** and **improve quality of life** for people with dementia.
- Consultees from all groups – workforce, carers and people with dementia – felt that the statements did **challenge current practice** and were aspirational.
- Generally, participants in the field testing felt that the **statements in the standard were clear**.

¹ Alzheimer's Society, *Dementia 2012*

- However, many statement-specific suggestions were given for improvement; these were described in detail in the report and NICE will want to consider these in full.

Points that were made that were relevant to all statements included:

- A need to check for jargon. In general people felt the statements were clear but there were some instances where jargon was felt to be used, including words such as “palliative” and “advocacy” that lay people may not understand, and perhaps even the need for a definition of “dementia”.
- A recognition that “carer” is defined to mean an unpaid carer, e.g. family or friend, rather than professional. This should come early on in the standard rather than statement by statement.
- It may be appropriate to include carers in some or all statements where they do not currently appear. However, it also needs to be acknowledged that not all people with dementia have the support of a carer.
- Often, integration between health and social care (and sometimes other stakeholders) will be key to realising the aspiration of the statements.
- There is a need generally, to be clearer about the ‘who, what, when’ in statements, but in particular ‘who will be responsible’. This may be supported by greater use of the active voice.

- Staff provided many examples of how they felt the standard could be used in practice, to **support dementia care quality and drive up standards**.
- **Guidance and training for social care staff** were recommended to support implementation.
- For people with dementia and carers, the key uses of the standard would be to **help challenge services**, get involved in discussions around **service provision** and to underpin complaints.
- The extent to which this would be possible would depend upon the extent to which the **standard is made accessible** to these groups, and **groups feel empowered** to use it.
- **Support from representative organisations, advocates and staff** was seen as important to enable them to utilise the standard.

- There was some concern expressed by field testing participants that **resource constraints** could limit the ability of the standard to drive up quality, and/or that the standard would need to be **enforced to ensure compliance**.
- **Integrated working between health and social care** was seen as key to successful implementation of the standard, as was **workforce development**.
- Important barriers affect **minority groups' access** to dementia care services, and this may need further acknowledgement within the standard.
- 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.

Conclusions

The field testing has demonstrated that there is a high degree of support for the dementia social care standard, both among social care staff and among people affected by dementia. Although many people are sceptical about the potential for change, most consultees felt that the standard was suitably aspirational, and if implemented, would improve quality of services above their current level.

The field testing highlighted however that implementation of the standard will be key to its success, and this was an area of concern for many participants. Consultees were unclear about the framework within which the standard will operate and the processes and activities which will bring it to life. There was a concern that in the current financial climate, the measures required to genuinely implement the standard and achieve aspirations would not be resourced, leading to disappointment.

The recommendations of the field testing are therefore to:

- review the wording and content of the standard, in line with the intentions of the field testing and the comments made by participants
- produce an EasyRead version and versions in other languages
- provide explanation of how the standard will be implemented, with supporting advice and guidance
- develop a programme of support around dissemination and implementation to ensure the standard does not stand in isolation.

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Annex A: Equality Impact Assessment (EqIA)

Annex B: Workforce survey questionnaire

Annex C: People affected by dementia – survey questionnaire

Annex D: Workforce invite to participate

Annex E: Workforce Participant Information Sheet

Annex F: Workforce focus group script

Annex G: Workforce interview topic guide

Annex H: People affected by dementia – invite to participate

Annex I: People affected by dementia – Participant Information Sheet

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

Annex K: People affected by dementia - focus group script

Annex L: People affected by dementia – interview topic guide

Annex M: Representative bodies interview script

Annex N: Profile of survey respondents

1. Introduction

Background and context

Dementia is one of the most important issues facing England as the population ages. There are estimated to be over 800,000 people in the UK with dementia and numbers are expected to double in the next thirty years.² Direct costs of dementia to the NHS and Social Care are in the region of £8.2bn annually.³

The Pilot Quality Standard for Dementia Care

In 2011, NICE took responsibility for developing quality standards for social care. An existing NICE Quality Standard for Dementia was launched in June 2010. The 2010 Quality Standard provided specific, concise quality statements, measures and audience descriptors to provide patients and the public, health and social care professionals, commissioners and service providers with definitions of high-quality care. While the 2010 standard was aimed at a broad audience, in light of the expansion of NICE's role to cover social care standards, a decision was taken to revisit the Quality Standard for Dementia and produce a new pilot standard encompassing the whole dementia care workforce, with a particular targeting of social care commissioners and providers.

NICE has developed the dementia care standard in partnership with the Social Care Institute for Excellence (SCIE) and with input from a Topic Expert Group (TEG) comprising key stakeholders. The TEG plays a key role in supporting NICE with the development of the standard.

The quality standard is intended to address effectiveness, user and carer experience of service provision, safety issues, equality and cost impact. It is derived from what is considered by NICE to be the best available evidence, such as NICE or other NICE accredited sources. This standard is intended to help the social care sector focus on delivering the best possible outcomes for people who use services. It is also intended to help people living with dementia, and their families and carers, understand what services they should expect from their care provider.

Groups that will be covered

- People living with probable or diagnosed dementia.
- Family and friends caring for people living with probable or diagnosed dementia.⁴

² Alzheimer's Society, *Dementia 2012*

³ Department of Health (2010) *Quality outcomes for people with dementia: building on the work of the National Dementia Strategy*

⁴ 'Carer' is used throughout this report to refer to unpaid carers rather than paid professional care workers.

The following subgroups of people living with probable or diagnosed dementia, who may need special consideration, will also be included:

- people younger than 65
- people facing barriers to accessing services
- people with characteristics protected by the [Equality Act 2010](#)
- people with learning disabilities.

Settings to be covered by the standard include all settings supporting people living with dementia with their social care needs, including:

- People’s homes (including assisted living accommodation).
- Residential care homes (with or without nursing care)
- Community-based settings (such as day care centres)
- Other settings where social care may be delivered, for example, primary, secondary and tertiary healthcare (including emergency departments, inpatient care and transitions between departments and services), hospices and prisons.

The field testing

Field testing is the testing of a piece of equipment or “tool” in the place where it is going to be used, rather than in a research laboratory.⁵ In the context of this study, field testing refers to taking the standards out to people who have dementia, their carers, and practitioners working in the dementia field, to test how the standards may be applied in practice.

The main purpose of the field testing was to assess the *relevance, usefulness, acceptability, clarity* and *potential impact* of the social care quality standard, through addressing the key questions set out below.

Table 2: Key questions to be addressed

- | |
|--|
| <ul style="list-style-type: none"> ▪ 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? ▪ 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? |
|--|

⁵ Cambridge Business English Dictionary.

Table 2: Key questions to be addressed

- In what ways do participants in the field testing envisage the quality standard being used?
- What support, if any, is needed to help stakeholders 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?

The brief specified that the field testing should be carried out with:

- professionals, commissioners and managers with responsibility for the care of people with dementia in the NHS, local authorities and the voluntary and private sectors including those involved in domiciliary care residential care (with or without nursing care), inpatient care, community care/nursing and social work
- people with dementia who have capacity to consent to involvement in this work (as purchasers of care and/or recipients of care), their families and carers (paid and unpaid)
- organisations representing the interests of people with dementia and/or those of their carers.

The field testing was undertaken on behalf of NICE by Skills for Care with Dementia UK. Skills for Care, established in 2004, is the employer-led champion of workforce development in the adult social care sector. Dementia UK is a national organisation, which aims to improve the quality of life for people with dementia and those that care for them.

2. Methodology

The key challenge for this work was to maximise participation from the diverse dementia care workforce and diverse population of people with dementia and their families. To tackle this issue we proposed a mixed methods approach that gave research participants the opportunity to be engaged in the way that most suits their personal preferences. This included individual interviews, running focus group events, and providing an online/paper survey.

Interviews with representative bodies

We undertook qualitative telephone interviews with representatives of six key national bodies:

- Dementia UK
- Alzheimer’s Society
- Carers UK
- Carers Trust
- Think Local Act Personal National Co-Production Advisory Group
- Association of Directors of Adult Social Services (ADASS).⁶

Focus group events with the dementia care workforce

We held three focus group events across the country aimed at the paid workforce for people with dementia. Attendees were sent a copy of the draft Quality Standards a few weeks before the event took place, and were asked to consider and apply the standards in their own workplace in line with the ethos of “field testing.” The focus groups then elicited views on how effectively attendees were able to apply the standards in their workplace and any lessons learned. Please see Annex F for the focus group guide.

We brought together two contrasting approaches in designing the focus group research, i.e. to both:

- focus “field testing” in a particular setting or settings
- mix up participants from a range of settings to bring together views.

The focus groups comprised of:

- a non-specialist residential care home for older people in the South East of England

⁶ A long list of potentially relevant representative bodies were identified in discussion with NICE, and each was sent an email invitation to participate in the telephone interviews. Only the six above were able to participate within the relatively tight timescale for the field testing. Some representative bodies also turned down the opportunity to participate as they preferred to respond to the consultation on the standard being run by NICE simultaneously.

- a specialist residential care home for people with learning disabilities, in the South West of England
- a mixed focus group involving participants from any setting, held at Skills for Care's Midlands office.

The care home focus groups were arranged via a direct approach from Skills for Care staff to care homes we were aware of through local networks. Both were involved in dementia care and had an interest in research. The mixed focus group was promoted to the social care workforce via Skills for Care's e-newsletter and through Skills for Care's local networks. Please see Annex D for a copy of the invite to participate.

A small number of one to one qualitative, depth interviews were undertaken with social care staff, by telephone, to supplement the focus groups. Please see Annex G for the topic guide. All focus groups and interviews with people affected by dementia and the workforce were audio recorded and written up as near-verbatim notes, with quotes directly transcribed.

Focus group events for people with dementia and carers

We held three focus group events across the country aimed at people with dementia and carers of people with dementia. Research suggests that focus groups can be an effective method of consulting with people who have dementia due to enhanced quality of interaction, reduced pressure on individuals to respond, mutual support, and the opportunity for shared experiences to trigger memory.⁷ Attendees were recruited from the networks of Dementia UK, Uniting Carers and Innovations in Dementia. Each was sent a plain language extract from the draft Quality Standards a few weeks before the event took place, to help them prepare (see Annex J for a copy of the material provided).

We held:

- one focus group aimed primarily at family carers
- one primarily aimed at people with dementia (carers able to attend if the person with dementia feels more comfortable)
- one mixed group of people with dementia and family carers.

Interviews with people with dementia and carers

People with dementia and carers were also offered one to one interviews rather than focus group participation. In addition to the focus groups, we interviewed 10 people with dementia and

⁷ Savitch, N., Zaphiris, P., Smith, M., Litherland, R., Aggarwal, N., & Potier, E. (2006).

Involving people with dementia in the development of a discussion forum – A community-centred approach. Published In 'Designing accessible technology' edited by John Clarkson, Patrick Langdon and Peter Robinson. Published by Springer-Verlag, London, 2006. pp237-248.

carers of people with dementia who were recruited through the membership and networks of Dementia UK.

On-line and paper surveys

The surveys were disseminated through Skills for Care and Dementia UK and partner networks. Respondents had the option of completing online or paper. Copies of the questionnaires used are appended at Annex B and Annex C. The aim of the online/paper surveys was to ensure that participants who could not come to the focus group events would still have the opportunity to participate, and to broaden the sample. The field testing could therefore reach a much larger group of people in a more cost-effective manner than might otherwise be the case. The surveys also provide useful quantitative data to back up the findings from the qualitative aspects of the field testing, i.e. the focus groups and interviews; and the demographic data collected has assisted in the equality impact assessment element of the work.

The surveys initially aimed to 400 social care workers and 200 people with dementia or carers. The achieved sample was 100 social care workers and 113 people affected by dementia. We believe that the main reason for the shortfall in expected numbers was the relatively short time period available for the survey element of the field testing, which of necessity ran over August, the traditional holiday month. We are unable to calculate a response rate for the surveys as they were not sent directly to individuals but the web link was promoted through Skills for Care and Dementia UK e-newsletters and other fora.

Analysis

Quantitative data was analysed using SPSS Statistics (software for statistical analysis). Descriptive statistics in the form of frequency tables were produced.

Qualitative data was analysed using Nvivo. This involved coding to identify key themes emerging from the data; and use of direct quotes where permission is given to help bring out the voice of the workforce, people with dementia and family carers.

Throughout this report the quantitative data is usually presented first, under each key research heading, followed by the richer information from the qualitative data.

Equality Impact Assessment

The key research questions include consideration of whether the draft Quality Standards may impact unevenly on people from different protected groups, and whether there are any adaptations to the standard that could be made to mitigate against such uneven impacts. Although specifically addressed in the research we suggested that an additional approach was taken, in line with the Equality Act 2010, by carrying out an Equality Impact Assessment (EqIA). This EqIA has been conducted by applying the principals of the 'public sector equality duty'

(PSED)—a set of regulations for how public sector bodies should implement the Equality Act 2010 in relation to the nine ‘protected characteristics’.

The approach involved a ten step process of assessment, but the primary aspect was to determine if there was any “differential impact” which involved reaching an informed decision on whether or not there is a differential impact on people sharing any of the protected characteristics. At the same time it was necessary to determine if the “differential impact” was positive, or indeed negative. If negative then the approach was to assess at what level this was and what should be done to address any adverse impact.

The Quality Standard for Dementia was reviewed by Skills for Care’s Programme Head for Research and Evaluation using the developed template and the aspects referred to assessed against each of the questions posed. The initial review comments were then reviewed and circulated for comments by the individual participants involved in the EqIA, prior to finalising. Participants included two representative bodies, one care home manager, and four recently bereaved carers, all from minority ethnic groups.

Sample frame

Our sampling approach was informed by *Methods for the Development of NICE Public Health Guidance (2009)*. This suggests primarily qualitative techniques for field testing, e.g. interviews and focus groups, which meant that probability sampling would not be appropriate.⁸ There was a need however to ensure a transparent approach that engaged all parts of the dementia care community.

We looked at data from the National Minimum Dataset for Adult Social Care (NMDS-SC)⁹, the NHS Information Centre and other relevant sources to estimate the size and structure of the workforce engaged in dementia care across sectors. We also looked at the Alzheimer’s Society’s report, *Dementia 2012*, for up to date statistics on the UK population with dementia.¹⁰

This enabled us to draw up a sampling strategy that ensured the full diversity of people with dementia, carers, practitioners, providers and commissioners could be engaged in the field

⁸ Marshall, MN. Sampling for qualitative research. *Family Practice* 1996; 13: 522-525.

⁹ Skills for Care (2011) Analysis of establishments that offer care and support for people with dementia.

¹⁰ According to the report, statistics for the UK population with dementia are as follows:

- 800,000 living with dementia
- 670,000 primary carers of people with dementia
- 60,000 deaths a year directly attributable to dementia
- 17,000 people of working age with dementia
- 11,500 people with dementia from black and minority ethnic groups
- women account for two thirds of people with dementia
- two thirds of people with dementia live in the community, one third in a care home
- around one third of people with dementia in the UK live alone.

testing. We devised a purposive sample for the qualitative exercises, based on targeting the desired audiences for the standard. Within the workforce element, NICE requested a focus on managers, supervisors and commissioners, who will play an important role in implementing the standard.

One of the care home-based focus groups was held in a local authority classified as Rural-80 by the Department of Environment, Food and Rural Affairs (Defra). Rural-80 districts have at least 80 percent of their population in rural settlements and larger market towns. The other care home was in a local authority classed as Other-Urban, districts with less than 26 percent of their population in rural settlements and larger market towns. The mixed workforce focus group was held in the urban area of Derby and attracted participants from a range of settings.

Table 2.1 below describes the target and achieved sample for the qualitative elements of the research.

Table 2.1 Sample frame for qualitative research

Focus groups and interviews		
	Target	Actual
Workforce		
Women	12	22
Men	4	2
Managers	9	10
Frontline workers, residential	8	7
Frontline workers, non-res	5	5
Total	24	24
People and families		
Women	17	18
Men	8	12
BME	2	6
People with dementia	14	12
Carers	14	18
Total	28	30

The achieved sample for the qualitative exercises was similar to the target sample, though we recruited slightly fewer people with dementia and slightly more carers than originally anticipated. This was due to expected difficulties in engaging people with dementia, for example unanticipated sickness preventing people attending interviews. Overall, there was a good response, dominated by carers but that did include the voice of 12 people with dementia, six within the survey and six within the qualitative exercises.

Annex N describes the profile of respondents to both surveys. The workforce survey was broadly representative of the social care workforce in relation to setting, with the majority of social care staff concentrated in the private sector. The survey sample also included 17 workers

who are employed in the health sector. Managers or supervisors made up 52% of the sample and there were three commissioners in the sample.

Total sample

Table 2.2 below provides a summary of the total participants involved in the field-testing, across the different research strands.

	Focus groups and interviews	Online/ paper survey	Total
Social care workers, managers and commissioners	24	100	124
People with dementia	12	6*	18*
Carers	18	97*	115*
Representative bodies	6	0	6

**These figures are likely to be a slight under-estimate as 10 respondents to the survey for people affected by dementia did not complete the demographic question at the end to identify which group they fell into.*

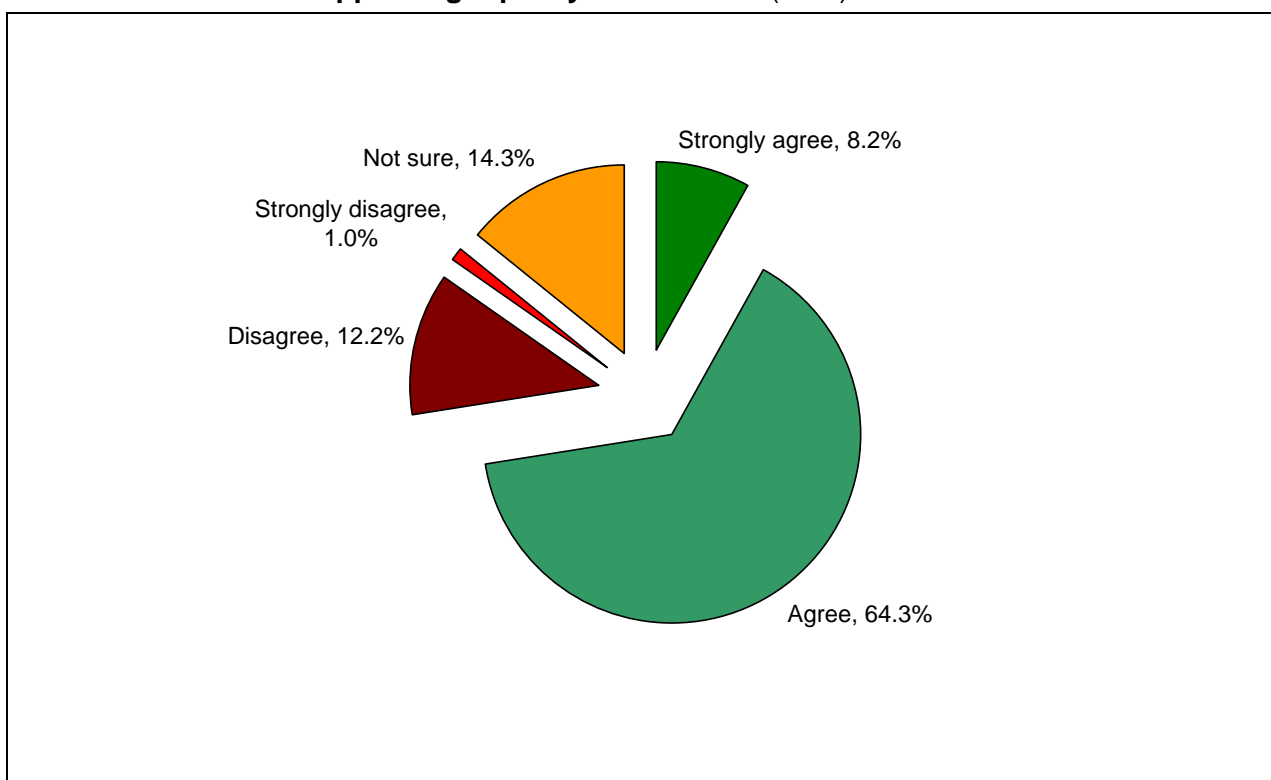
3. Findings – the standard’s ability to support quality care

An overarching question for the field testing was whether the standard has the ability to support the quality of care. Key to understanding this is whether the standard reflects or challenges current practice adequately. Participants in the field testing were asked to feed back their views in response to these issues.

Ability to support quality of care

Most staff who responded to the survey, agreed that the standard will support high quality care (72.4%). There were no significant differences between respondents from different sectors or job roles.

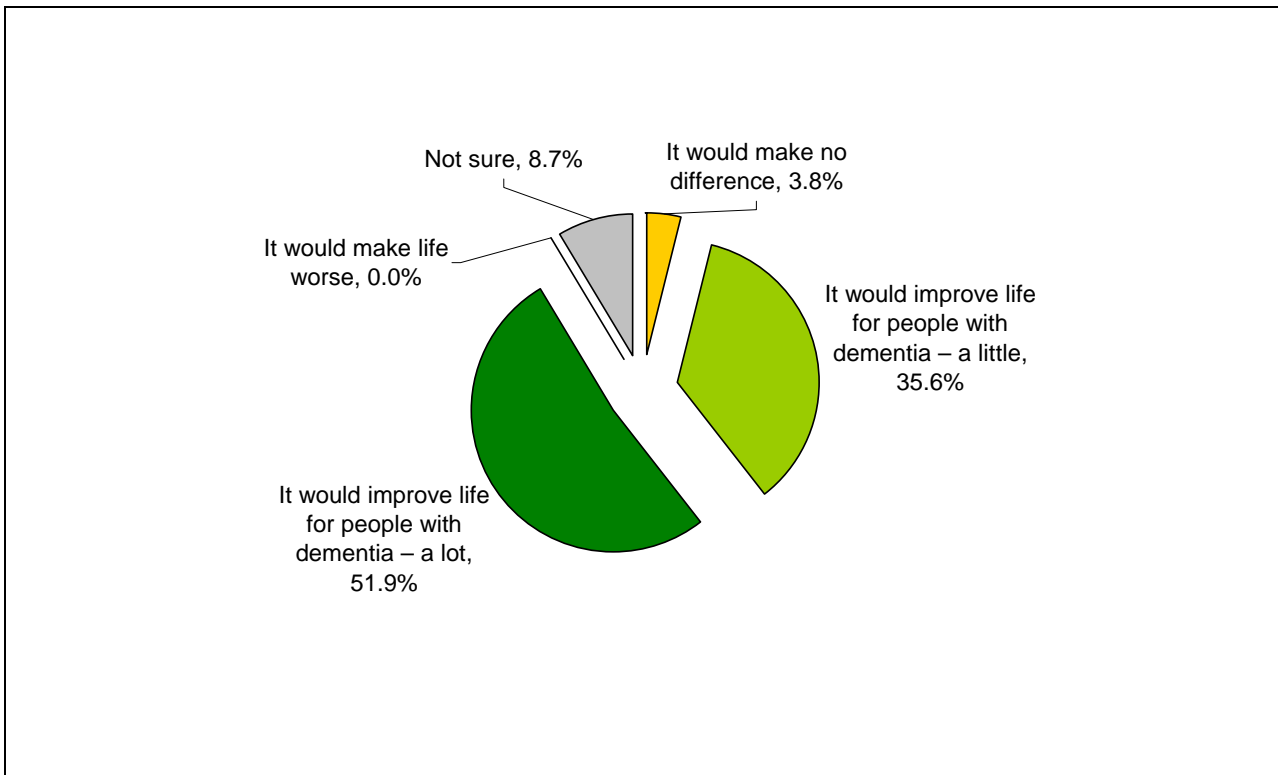
Table 3.1: To what extent do you agree or disagree that, taken as a whole, the standard in its current form will support high quality social care? (Staff)



N=98. Excludes 2 non respondents.

People affected by dementia who responded to the survey were overwhelmingly positive about the ability of the standard to support quality of care. Only 3.8% felt it would make no difference and over half thought it would improve life ‘a lot’ for people with dementia. There were no significant differences between people with dementia and carers.

Table 3.2: Would people with dementia have a better life if this standard was met?
 (People affected by dementia)

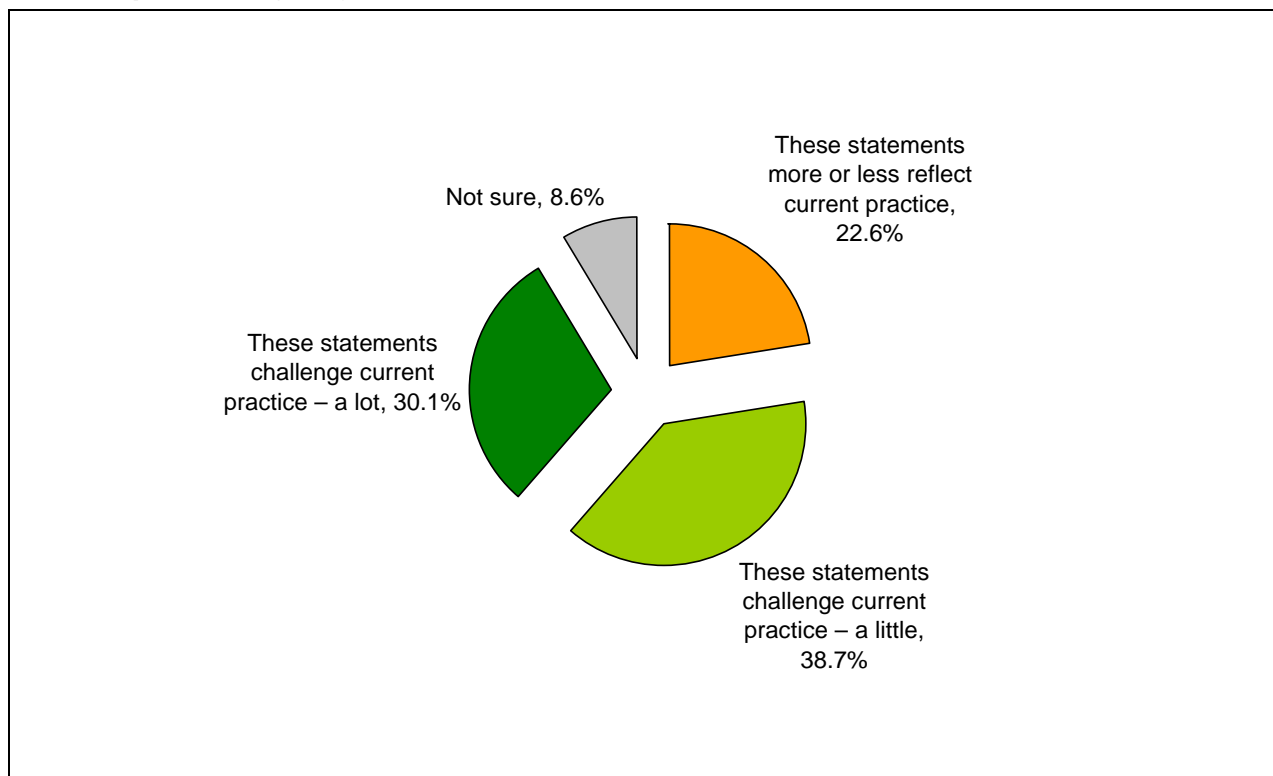


N=104. Excludes 9 non respondents.

Challenging current practice

Participants in the field testing were asked to what extent they felt the statements reflected current practice, or challenged it. Most staff who responded to the survey (68.8%) felt that the statements did challenge current practice. There were no significant differences between respondents from different sectors or job roles.

Table 3.3: To what extent do the statements in the quality standard reflect or challenge current practice? (Staff)



N=93. Excludes 7 non respondents.

Generally, the feeling from the qualitative exercises was that the statements challenged current practice, with only rare comments that they reflected current practice.

“I think it reflects some current practice, e.g. it talks about involvement and consultation with people and carers. It talks about care and support needs planning. But I think it does go further than that in looking at end of life care and holistic wellbeing linked to community.”

- Representative body

People mostly welcomed the standards and felt they were aspirational, which was seen as a positive step.

“We should always be striving not just to be the minimum but to think about best practice.”

- Staff member, focus group attendee

This view was common across staff, representative bodies and people with dementia and carers involved in the research. Consultees felt that reaching the standard would be challenging, even idealistic, but that this was a positive as services needed to be improved.

“Here in [my local authority area] it will challenge us a lot. Most directors would not disagree with what we aspire to but to be held to account to what the standard aspires to is going to be challenging.”

- Commissioner

“[The standard is] going to create [a] training need but that training need is going to have to come out of existing budget and that is the challenge as there is little funding available.”

- Staff member, focus group attendee

Summary

The vast majority of participants felt that the standard will support high quality social care and improve quality of life for people with dementia. Consultees from all groups – workforce, carers and people with dementia – felt that the statements did challenge current practice and were aspirational.

4. Statement-specific findings

Both staff and people affected by dementia were asked about their views on the clarity of statements, during the survey work. Table 4.1 below highlights the statements that were most commonly (dark grey), or least often (light grey), assessed as clear.

Interestingly, there were few major differences in the views of staff vs. people affected by dementia. An overwhelming majority (over 70%) of respondents in all cases felt the statements were either quite or very clear. Perhaps unsurprisingly, people affected by dementia were in most cases less likely to rate the statements as clear, than staff – on average by 3.2 percentage points.

Both staff and people affected by dementia were most likely to rate statement 6 as clear (“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”).

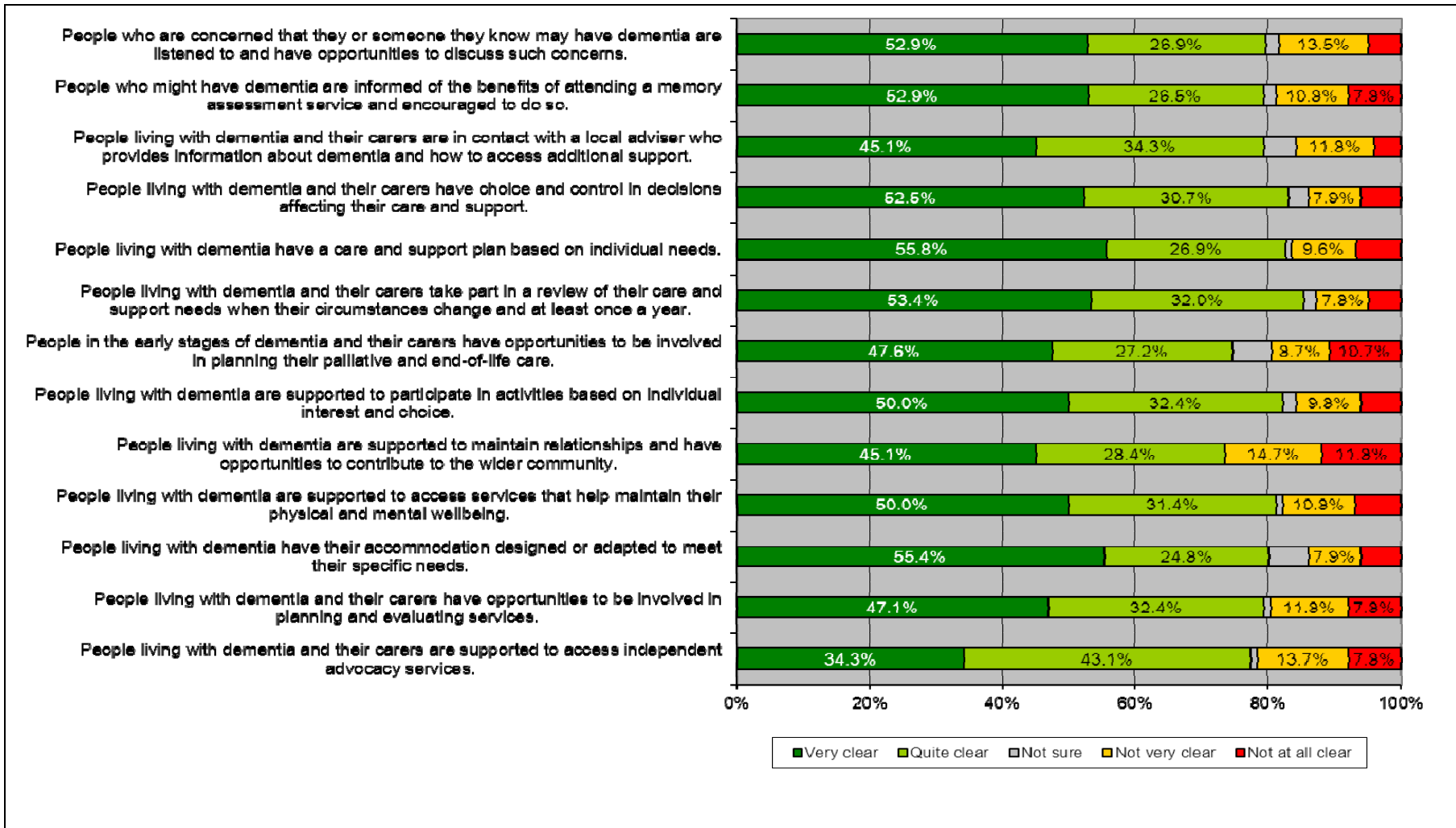
People affected by dementia were least likely to rate statement 9 as clear (“People living with dementia are supported to maintain relationships and have opportunities to contribute to the wider community”), while staff were least likely to rate statement 11 (“People living with dementia have their accommodation designed or adapted to meet their specific needs”) or 13 (“People living with dementia and their carers are supported to access independent advocacy services”) as clear.

Table 4.1: Proportion of survey respondents rating the statement as ‘quite’ or ‘very’ clear

Statement	Staff	People affected by dementia	Difference
1. People who are concerned that they or someone they know may have dementia are listened to and have opportunities to discuss such concerns.	81.9%	79.8%	-2.1%
2. People who might have dementia are informed of the benefits of attending a memory assessment service and encouraged to do so.	84.0%	79.4%	-4.6%
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.	83.0%	79.4%	-3.6%
4. People living with dementia and their carers have choice and control in decisions affecting their care and support.	81.1%	83.2%	2.1%
5. People living with dementia have a care and support plan based on individual needs.	88.4%	82.7%	-5.7%
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.	89.5%	85.4%	-4.0%
7. People in the early stages of dementia and their carers have	83.0%	74.8%	-8.2%

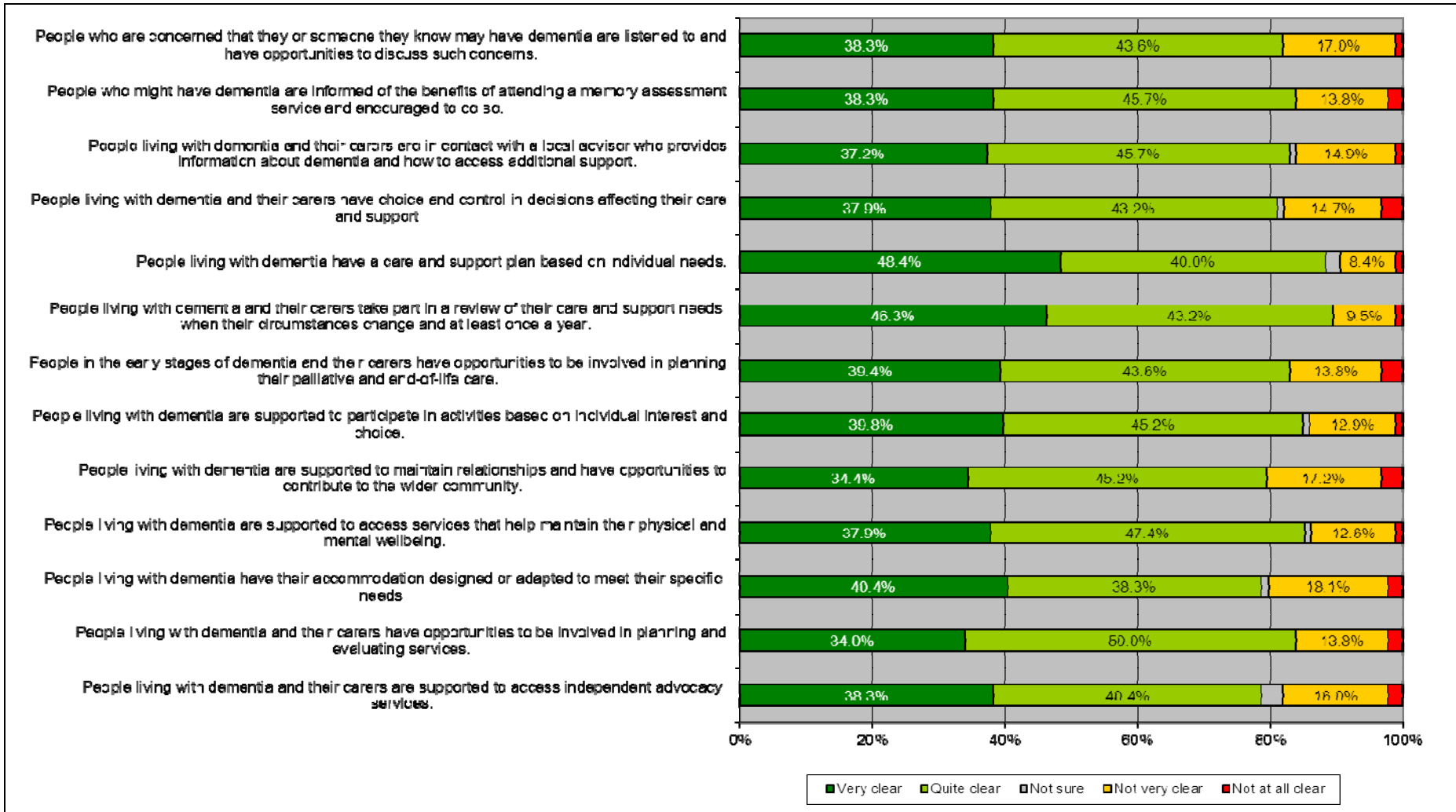
Statement	Staff	People affected by dementia	Difference
opportunities to be involved in planning their palliative and end-of-life care.			
8. People living with dementia are supported to participate in activities based on individual interest and choice.	84.9%	82.4%	-2.6%
9. People living with dementia are supported to maintain relationships and have opportunities to contribute to the wider community.	79.6%	73.5%	-6.0%
10. People living with dementia are supported to access services that help maintain their physical and mental wellbeing.	85.3%	81.4%	-3.9%
11. People living with dementia have their accommodation designed or adapted to meet their specific needs.	78.7%	80.2%	1.5%
12. People living with dementia and their carers have opportunities to be involved in planning and evaluating services.	84.0%	79.4%	-4.6%
13. People living with dementia and their carers are supported to access independent advocacy services.	78.7%	77.5%	-1.3%
Minimum	78.7%	73.5%	-5.2%
Maximum	89.5%	85.4%	-4.0%
Median	83.0%	79.8%	-3.2%

Table 4.2: For each statement, please tell us whether you think it is clear (People affected by dementia)



N=101-104

Table 4.3: For each statement, please tell us whether you think it is clear (Staff)



N=93-95

Further detail was provided from the qualitative exercises, i.e. the focus groups and interviews with staff, people affected by dementia and representative bodies; and from the open questions within the surveys. This feedback is detailed statement by statement, below. For each statement, we include a brief summary of the ways in which consultees felt that the statement could influence social care practice. At the end of the chapter, we summarise suggested improvements that were made.

Statement 1: People who are concerned that they or someone they know may have dementia are listened to and have opportunities to discuss such concerns.

Key themes that emerged from the discussions around Statement 1 included:

- concerns around the practicalities of implementing this statement, and the difficulties around the diagnosis of dementia
- the need for recognition that the responsibility for listening to people around dementia goes much further than the social care workforce
- the need for integrated working between health and social care
- a need for the language to be more specific, for example, who will be responsible for undertaking particular activity.

Several comments – both from people affected by dementia and staff – identified the key question of ‘*who will listen?*’. Some felt sceptical that this would happen; others pointed out that the first person to listen is unlikely to be a social care worker and may either be a GP or someone from the community. Several comments related to the skills of GPs in relation to early diagnosis of dementia and felt that more needed to be done with this group of professionals, though it falls outside the scope of the social care standard.

“If you go to the doctor, like I did, she just didn’t want to listen... Unless you get past the doctor there is no point being listened to by other people.”

- Focus group attendee with dementia

The general implication was that this would be a statement that will challenge current practice because often at present people do not feel listened to. This is compounded by the fact that people often can be in denial about the onset of dementia, as there is still a stigma around a diagnosis, in all communities, but especially in some ethnic minority communities.

“This is profoundly weak, especially for those with young onset. In our case we talked for four years about concerns before they were taken seriously and I know of 10 other couples who had the same thing because doctors are far more likely to put it down to stress, overwork, all those kinds of things.”

- Carer, focus group attendee

Some felt that to fully operationalise this statement would require a public awareness raising campaign to create an environment in which people would be listened to, and would be empowered to come forward with concerns.

“As a community we need to be working on it...I am working with our community on dementia friendly communities...the challenge that you’ve got is that the community doesn’t know what it should be listening out for.”

- Practitioner interviewee

There was also a comment about the outcomes linked to this statement – being listened to is one thing, but concerns being acted on another, especially where someone may not be eligible for funded support. One group raised a question as to how feedback will be collected to monitor this statement and there was a feeling that compliance did need to be enforced.

How will Statement 1 influence social care practice?

- Challenges for universal staff on their knowledge of where to signpost people for support
- Build links between specialist and universal services
- Help focus on early symptoms.
- Improve consistency of approach for people in early stages of dementia
- Challenge the ability of current social services to listen, regardless of funding eligibility.

Statement 2: People who might have dementia are informed of the benefits of attending a memory assessment service and encouraged to do so.

Some similar concerns arose in relation to Statement 2, relating back to the points made for Statement 1 about the need to include GPs, and the difficulties of diagnosis. One point was made that family, friends and the wider community should also be informed of the benefits of a memory assessment service, so they can help encourage the person with dementia. One person suggested that people who have already been diagnosed could be involved in encouragement and peer support.

One practitioner interview suggested the word “enabled” as was felt this required more action than implied by “encouragement”. For example this might require active support such as transport or an advocate.

How will Statement 2 influence social care practice?

“We have a responsibility to make sure that when we have [an] enquiry that we actually follow this up and even if they don’t have a diagnosis, we keep an eye out for changes in behaviour and we have the confidence to get a referral through to the memory assessment services if needed.”

- Staff member, interviewee

Statement 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.

This was an area where it was suggested that there is currently a gap and the statement would challenge current practice.

“We are fighting locally against dementia being rolled up with everything else in mental health. It is cutting out the experts, who are more helpful on neurology. So it is about the skill, knowledge and expertise. It needs to be specialist, not generic, for it to be helpful.”

- Carer, focus group attendee

Questions were raised about whether this statement could be implemented in practice (given the availability of resources), and who the local adviser would be.

“There would need to be very clear job descriptions to make plain to the adviser, the person with dementia and carers, and health professionals what their role entails - is it just signposting or does it include some counselling element, for example.”

- Interviewee with dementia

Specific suggestions for improvement were received, including:

- define the word ‘local’ – does this mean local authority?
- add the word ‘specialist’ (before ‘adviser’)
- may wish to include that information should be ‘time-appropriate’

Key points that emerged from discussion included the view that the adviser role may need to be about more than just providing information and a list of additional phone numbers – people can find this overwhelming.

“[The] needs of people with dementia care can be serious and urgent – related to signs of distress or behaviour patterns that put the carer at risk – not just needing a list of local support groups. Don’t want to hear from the advisor ‘I can’t deal with that’ – that is very frustrating... There is a limit to how many phone calls you have the energy to make. It [support] needs to be immediate in terms of time and geography.”

- Carer interviewee

“It is the walking, talking face of the pack you are given at diagnosis. Information needs to be mediated, you need to be able to ask questions, not just have leaflets.”

- Carer, focus group attendee

It was also queried who needs to initiate the contact – would this come from the service or from the person with dementia/ their carer.

How will Statement 3 influence social care practice?

- Reduce the current differences across the country: *“so if people transfer from different counties they know what to expect.”* [Staff interviewee]
- Provide clarity locally to identify who the local advisor(s) are and make sure people know what they can offer.

“We would need to think more about how to give people information when they need it and when it’s right for them.”

- Staff member, focus group attendee

Statement 4: People living with dementia and their carers have choice and control in decisions affecting their care and support.

The key theme in relation to this statement was around the scope of choice and control and how this would vary between people with dementia and carers; and vary for people with dementia depending on the stage of illness.

“‘Control’ and ‘decisions’ depend on how far you are in the illness, whether you are capable of doing things yourself or whether you need 24 hour support.”

- Person with dementia interviewed

“People with dementia can get to the point where the concept of choice and the concept of control becomes more and more limited... That’s where someone has to enable them to make the choices, or make the choices for them. What happens if you section people. What happens if you have to put the carer’s choices above the choices of the person with dementia.”

- Carer interviewee

Comments were received that suggested the word choice might be more clearly defined and that this statement may need to be qualified by a ‘where possible’.

How will Statement 4 influence social care practice?

- Clarity about what to expect.

“This could keep things clear, simple, transparent, something that obvious for people to rate the service.gives guidelines for those that want to improve”

- Staff member, focus group attendee

Statement 5: People living with dementia have a care and support plan based on individual needs.

Again, this was an area where some carers felt that the statement posed a challenge to current practice. While some carers knew the person they were caring for had a plan, and that is was useful, others felt this was a gap.

“We’ve got a care co-ordinator who works up our care plan, but we only ever had one in September 2009. It’s never been updated...”

“We have never had a ‘document’...”

“Planning has been going on but it has all been ad hoc for us. It might be quite light touch at the first, but it would be enormously helpful for someone to sit down with you after diagnosis and say, let’s see what needs to happen over the next six months.”

- Carer discussion, three focus group attendees

It emerged from the discussions that sometimes people with dementia can have multiple care and support plans produced by different agencies, or (for example) one for social care and one for health. The feeling was that the statement could be clarified to make it clear that there

should be a single co-ordinated care plan, beginning from diagnosis and led by a named individual, which might either be a carer or a professional.

“It’s got to be one plan, one co-ordinator. We never get the joined up writing. It’s a little here, a little there. We need it all together.”

- Carer, focus group attendee

It was also seen as important that the person with dementia and their carer should be centrally involved in developing the care plan and hold their own copy.

“It is empowering if the care plan sits at home with me - there might be copies elsewhere, but there is a copy with me.”

- Carer, focus group attendee

There was also a question around some of the measures in this section such as why personal budgets were mentioned again in the draft measures section.

How will Statement 5 influence social care practice?

- Clarity & consistent approach to care and support planning with key decisions and activity located in one area to support decision making and future choices.

Statement 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.

This was a statement that many carers felt was aspirational and would challenge and improve current practice. Key issues raised in relation to this statement tended to centre around the need to define who would be responsible for initiating and completing the review. It was also commented that the review should include all relevant documentation, e.g. a log of support provided.

Some carers and some professionals involved in discussions felt that annually was too infrequent and that six months should be the recommended frequency. It was also queried how ‘circumstances changing’ would be defined and whether there was a need to clarify this within the statement; and one group suggested that ‘their circumstances’ ought to be changed to simply ‘circumstances’.

How will Statement 6 influence social care practice?

- Greater focus on involving people with dementia and their carers in care and support planning

Statement 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.

As with other statements, discussion around Statement 7 highlighted the feeling that it should be clearer ‘who’ will be planning palliative and end of life care. It was suggested by some that this might be health professionals in the palliative field.

“Who does this planning with you? There should be someone but it doesn't say who and if it doesn't it probably won't happen. People in the palliative care field preferably, please.”

- Carer, focus group attendee

One group pointed out that this statement should not be limited to people in the early stages of dementia, as this opportunity should be open to people at all stages, especially if diagnosed late or did not have the opportunity for end of life care planning earlier in their journey. It was also queried what the definition of involvement should be (emphasising the need to avoid jargon), and consultees emphasised that the opportunity to engage in end of life discussions will always need to be offered sensitively.

“People don't understand dementia and having them ask about end of life care and palliative care needs to be sensitively done and timing right – needs rapport and understanding.”

- Residential care worker, focus group attendee

How will Statement 7 influence social care practice?

- Consider future wishes in a timely manner.

Statement 8: People living with dementia are supported to participate in activities based on individual interest and choice.

During a focus group it was pointed out that beliefs and spiritual needs were not reflected in the statements and therefore adding “and beliefs” could be needed.

In relation to this statement in particular, many people felt it was not sufficiently well defined, in particular relating to the ‘who’ and ‘how’. This was seen as critical to effective monitoring.

“ ‘Participate in activities based on individual interest and choice’ could cover so many things. In some ways I can see why you wouldn’t want to restrict it, precisely because its about someone’s ‘individual interest and choice’ but at the same time I think that there are some common things that people with dementia tend to want (for example, peer support – having a chance to meet with others in their situation – is, in my experience, really important to people with dementia)...

The statement could be improved if it included some examples of things that are generally accepted to be of interest to people who are experiencing any kind of challenging experience in their life. For example, talking to other people in a similar situation, being able to continue with activities that you did before you developed dementia.”

- Representative organisation

Some concerns were expressed around the achievability of the aspiration in the statement, in relation to resources available:

“You need to be able to increase funding to increase participation”

- Staff member, focus group attendee

How will Statement 8 influence social care practice?

- More attention and effort given as to how services find out what people are interested in, especially if there are communication difficulties, or lack of family/close friendships
- Reaction in community to people with dementia taking part in things – stigma still associated with dementia
- Challenge given lack of resources
- Creative thinking about how to involve without additional costs.

“[My employer isn’t] a task based organisation and we are more about stimulation and conversation and talking to clients for the people that they are as opposed to tasks needing done. Our training focuses on engaging with broader spectrum of work e.g. we play dominos, take people for a drive etc depending on what they were interested in before the dementia.”

- Staff member, interviewee

Statement 9: People living with dementia are supported to maintain relationships and have opportunities to contribute to the wider community.

This statement was seen as one where sensitivities around equality and diversity were particularly important. For example, it was commented that:

- Many LGBT people (and other people) with dementia are living alone and have ‘families of choice’. Professionals will want to ask people about ‘significant others’ or ‘people who matter’ rather than cause distress by assuming significant relationships would only include a spouse, children or family of origin.
- Services for people with dementia, e.g. residential homes, should be culturally sensitive to the LGBT community. Bigotry from residents should not be tolerated purely because it comes from older people; *‘Friends visiting might hug and kiss you as this is what happens in normal circumstances in the gay community.’* [Person with dementia, interviewee].
- Within some ethnic and religious groups there is still a serious stigma about dementia, which can affect both people with dementia and carers. This means that people affected by dementia in these groups can feel rejected by their communities and may need support.

It was also commented that there is a stigma more generally within all communities, and work needs to be done to change this and allow the aspiration of the statement to be achieved. One member of the workforce cited as good practice a memory clinic they are aware of where group psychotherapy is provided to people with dementia and social networks instigated.

Some queries were raised in relation to the measurement of this statement and the definition of relationships. Some people felt this would include relationships with professionals, but highlighted that building strong relationships with professionals required continuity of care, and adequate resourcing:

“We don't have the time to do the relationships stuff in the current timescale that we have to do everything that we need to do 15 minute blocks of time.”

- Staff member, focus group attendee

At least one other member of the workforce however felt that this good practice already took place, and the standard only supported current practice.

How will Statement 9 influence social care practice?

- Challenges the practice of commissioning domiciliary support in fifteen minute time slots
- Continuity of staff will be required to help build relationships between people and paid carers
- Services will need to recognise people as individuals
- Staff will need to think about how to help people stay in the community and what facilities or social networks there are they could connect to locally
- *Your Story Matters* approach to help understand people's journey and important relationships.
- Social care seen as more than immediate service and the need to consider wider community development.

Statement 10: People living with dementia are supported to access services that help maintain their physical and mental wellbeing.

Generally, this statement was welcomed strongly by consultees. It was felt that the statement was challenging to current social care practice and might require resourcing, e.g. could not be provided within a 15 min window (see above).

“I had no support for three and a half years. I had no means of knowing if my dementia was getting worse and without proper follow-up there was no one to monitor me and ask how I was maintaining my physical and mental wellbeing. I was going to routine heart checks once a year, but they were not there to talk to me about the dementia side of it. I needed to have someone I trusted who had more up-to-date knowledge and could be someone I could have half and hour's conversation with.”

- Person with dementia interviewed

As with some other statements, it was commented that this statement was broader than the social care workforce and would require buy-in from the health workforce to be achieved. It was suggested that this could be built into the care plan and reviews.

This statement was also one where carers particularly felt that it was important for their role to be acknowledged, as carers' health and wellbeing will also impact the wellbeing of the person with dementia being cared for, and demand for services.

Some suggestions were received around defining 'support' more clearly and explaining who would be responsible for providing it. One group suggested that spiritual wellbeing also should be added to the statement to include people with faith and spiritual beliefs.

How will Statement 10 influence social care practice?

- Provides an opportunity to promote advocacy
- Challenges the practice of commissioning domiciliary support in fifteen minute time slots
- Challenges staff on their knowledge of where to signpost people for support.
- Support of the whole person, not just focus on their "condition"

Statement 11: People living with dementia have their accommodation designed or adapted to meet their specific needs.

Issues raised around this statement included the question of who would adapt the accommodation, or pay for it, and whether the statement should really be about making people aware of what is available and how to access it.

"This is a long drawn-out process involving an OT [occupational therapist], surveyors, contractors, finance. It needs to be in the care plan, specifying how the process will occur. OTs in our borough were very difficult to contact. The statement does not say who will set the process in motion. It also does not specify different circumstances, such as if the house is owned by someone else."

- Carer interviewee

Participants in the staff focus group who worked with clients with learning disabilities felt strongly about this. They felt there was a need to try to keep people in their own environment even with dementia and that sometimes people with learning difficulties could be moved to generalist dementia care rather than staying in a specialist familiar environment, with additional dementia input/ awareness.

There were also concerns that this statement might not always be realistic – need to be careful not to give people false hope that their house can be adapted. Alternatively, staying at home might not always be the best option for the individual – individuals may need more intense support than can be offered at home.

One staff group raised the issue of training – who will assess if the house is suitable for adaptation and what adaptations are needed? Are staff trained to do this? At a low level, common sense but what happens further down the line?

How will Statement 11 influence social care practice?

- May require staff training to acquire knowledge in assessments and adaptations.

Statement 12: People living with dementia and their carers have opportunities to be involved in planning and evaluating services.

In relation to this statement, consultees highlighted that involvement must be genuine and not simply “tokenistic”. Outcome measurement should involve looking at feedback and what happened as a result of involvement, not simply involvement itself.

It was also commented that not all people with dementia have a family carer who can be involved, and there may be a role for a professional e.g. an advocate to be involved on their behalf. It may also be appropriate to involve representative bodies as a way of ensuring that wider community views are represented and not simply those of a very small number of people.

Capacity building can also be important to empower people to become involved:

“Networking meetings and buddying might be a way to encourage participation, such as using carers meetings or dementia cafe groups for experienced carers to encourage newer carers to get involved in influencing services through telling their stories of how they have been involved in shaping services and encouraging others to get involved.”

- Carer interviewee

How will Statement 12 influence social care practice?

- Requires flexibility and personalised approach.
- Services genuinely designed by people receiving them
- Ability to capture feedback in appropriate ways – especially if there are communication difficulties [potential learning from LD services]
- Timing of when information is collected and how the information is used

Statement 13: People living with dementia and their carers are supported to access independent advocacy services.

Feedback suggested that this was a statement that would challenge current practice, as not all carers and people with dementia currently had access to an advocate.

“I went looking for these advocates and couldn’t find them. I would have loved an advocate when me and my dad were having arm wrestles, trying to get the car keys off him and all the times when he went missing. He could have killed himself in that two years before he got a diagnosis.”

- Carer, focus group

There were some concerns related to this statement that advocacy is a service under threat from austerity and that resourcing may be a barrier to implementation. It was also commented that to be successful, advocacy has to be able to draw on other services, and that it needs to be an ongoing contact. Some people felt that paid carers should also be able to access advocacy services on their clients’ behalf. Several comments highlighted the limitations with advocacy services – time, resource, dependence on other agencies, lack of ability to enforce – however the statement was still generally welcomed.

How will Statement 13 influence social care practice?

- Requires flexibility and personalised approach.
- Emergence of more dementia advocacy roles / services
- Challenges of staff knowing who the advocacy services are locally and how/when you are able to access and use.

Summary of improvements suggested

The table below summarises the improvements suggested to each specific statement.

Table 4.4 Summary of improvements suggested

Statement	Summary of improvements suggested
Statement 1	<ul style="list-style-type: none"> ▪ Recognise that the responsibility for listening to people around dementia goes much further than the social care workforce ▪ Improve specificity throughout ▪ Specify who will be responsible for undertaking particular activity ▪ Consider what will be needed to implement, e.g. public awareness raising campaign

Statement	Summary of improvements suggested
	<ul style="list-style-type: none"> ▪ Consider whether the apt outcome measure would be ‘listened to’, or ‘concerns acted upon’, and how this would be monitored.
Statement 2	<ul style="list-style-type: none"> ▪ Family, friends and the wider community should also be informed of the benefits of a memory assessment service ▪ Consider how to implement, e.g. peer support ▪ Replace the word ‘encourage’ with ‘enable’.
Statement 3	<ul style="list-style-type: none"> ▪ Specify who the local adviser would be ▪ Specify what the role will involve and the balance between advice only and support ▪ Consider how to implement ▪ Define the word ‘local’ ▪ Add the word ‘specialist’ (before ‘adviser’) ▪ Add that information should be ‘time-appropriate’ ▪ Specify who needs to initiate the contact.
Statement 4	<ul style="list-style-type: none"> ▪ Define the word ‘choice’ ▪ Qualify by a ‘where possible’.
Statement 5	<ul style="list-style-type: none"> ▪ Clarify that there should be a single co-ordinated care plan, beginning from diagnosis and led by a named individual, which might either be a carer or a professional ▪ Clarify that the person with dementia and their carer should be centrally involved in developing the care plan and hold their own copy. ▪ Review whether personal budgets should be included in the draft measures section.
Statement 6	<ul style="list-style-type: none"> ▪ Define who would be responsible for initiating and completing the review ▪ Specify the scope of the review ▪ Review the recommended frequency of the review ▪ Define ‘circumstances changing’ ▪ Change ‘their circumstances’ to simply ‘circumstances’.
Statement 7	<ul style="list-style-type: none"> ▪ Clarify ‘who’ will be planning palliative and end of life care ▪ Do not limit to people in the early stages of dementia.
Statement 8	<ul style="list-style-type: none"> ▪ Add “and beliefs” ▪ Clarify ‘who’ and ‘how’ undertaken.
Statement 9	<ul style="list-style-type: none"> ▪ Clarify that relationships may include others than spouse, children or

Statement	Summary of improvements suggested
	family of origin, i.e. may include civil partners, unmarried couples, friends or professionals.
Statement 10	<ul style="list-style-type: none"> ▪ Consider resources needed for implementation ▪ Recognise support from health workforce needed ▪ Define 'support' more clearly ▪ Explain who would be responsible for providing it ▪ Add 'spiritual wellbeing'.
Statement 11	<ul style="list-style-type: none"> ▪ Specify who would be responsible for adapting the accommodation ▪ Consider whether the statement should instead be about making people aware of what is available and how to access it. ▪ Consider implementation measures required e.g. resource, training.
Statement 12	<ul style="list-style-type: none"> ▪ Outcome measurement should look at what happened as a result of involvement, not simply involvement itself ▪ Involvement could include a paid carer or representative body. ▪ Consider implementation measures needed, e.g. capacity building.
Statement 13	<ul style="list-style-type: none"> ▪ Consider resourcing needed for implementation ▪ Paid carers should also be able to access advocacy services on their clients' behalf. ▪

Points that were made that were relevant to all statements included:

- A need to check for jargon. In general people felt the statements were clear but there were some instances where jargon was felt to be used, including words such as “palliative” and “advocacy” that lay people may not understand, and perhaps even the need for a definition of “dementia”.

“It is written in civil service language. It needs to be written in words the person with dementia and those next to them can understand.”

- Carer, focus group attendee

- A recognition that “carer” is defined to mean an unpaid carer, e.g. family or friend, rather than professional. This should come early on in the standard rather than statement by statement.

- It may be appropriate to include carers in some or all statements where they do not currently appear.

“There is a symbiotic relationship between carer and cared for. It needs to be seen as one thing, with the carer’s needs acknowledged.”

- Carer, focus group attendee

- However, it also needs to be acknowledged that not all people with dementia have the support of a carer.
- Often, integration between health and social care (and sometimes other stakeholders) will be key to realising the aspiration of the statements.

“We would like everything to be joined up. Wherever you go you get access to everything else. We don’t care who does it, so long as we get the desired result.”

- Carer, focus group attendee

- There is a need generally, to be clearer about the ‘who, what, when’ in statements, but in particular ‘who will be responsible’.

“It is ambitious and there is a lot in it that could really make things better for people in my situation.... Generally the details is missing - a more thorough description to help commissioners, for example, would help to make the statements more explicit.”

- Interviewee with dementia.

5. Findings – Implementation

Implementation of the standard covers two key issues:

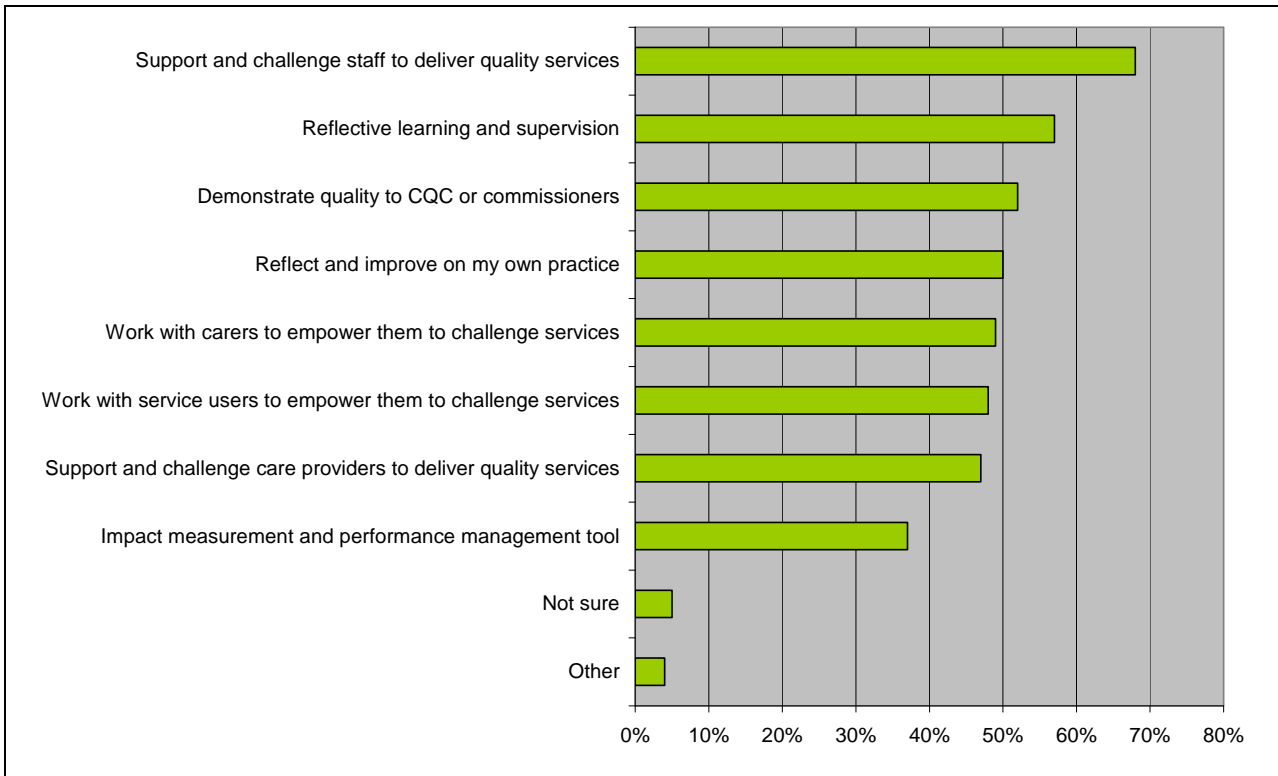
- implementation of the social care standard within the social care workforce
- empowering people affected by dementia to support and challenge services to ensure implementation.

Use of the standard by staff

Staff responding to the survey were asked, in a multi-choice question, how they think they might use the quality standard in practice. The most common response was “to support and challenge staff to deliver quality services” (68%). This is perhaps expected given the high proportion of managers/supervisors within the survey sample (52%). More than half of respondents also said they would use the standard:

- in reflective learning and supervision (57%)
- to demonstrate quality to the Care Quality Commission (CQC) or commissioners (52%).

Table 5.1: How do you think you will use the Quality Standard in practice? (Tick all that apply) (Staff)



Suggestions made by staff and representative bodies within open questions, or during the qualitative exercises, as to how they would use the standard included those in the table below.

Table 5.2: Further suggestions on using the standard (workforce)

Suggestion	Comments/ examples
Benchmarking	<ul style="list-style-type: none"> ▪ Adapt the standard to become a badge or star system ▪ Social care organisations use the standard to develop internal Key Performance Indicators (KPIs) <p><i>“The old saying 'say what you do, do what you say and then prove it!' could be applied to the standard and used maybe as a checklist for service users and family members and carers too make sure services are meeting individual needs.”</i></p> <p style="text-align: center;">- Staff member, focus group attendee</p>
Within workforce development; to inform training and competency requirements	<p>Use standard to:</p> <ul style="list-style-type: none"> ▪ develop competencies for managers ▪ develop training programmes for staff ▪ inform qualifications
To inform service specifications	<p><i>“For my team we will use them to ensure that all of our service specifications refer to the statements, where appropriate. Our specifications will also include the evaluation of those services.”</i></p> <p style="text-align: center;">- Representative body</p>
As part of disseminating information on dementia and dementia care	<ul style="list-style-type: none"> ▪ Use by agencies ▪ Dementia information days ▪ Promotion by representative bodies
Good practice handbook	Internal manual for social care organisations
To empower service users	<p>Ensuring that service user groups are made aware</p> <p>Facilitating service user involvement</p> <p>Offering meeting places if appropriate to enable connections to be made</p>
Research	Including practice development

Further comments were reported under ‘statement-specific findings’ in Chapter 4.

Use of the standard by people affected by dementia

People affected by dementia who responded to the survey were asked, in a multi-choice question, whether they felt they would be able to use the standard to make life better. It was apparent from the responses that there was some doubt as to whether people affected by dementia themselves felt empowered by the standard. Just over half of respondents felt they would be able to use the standard in most examples given.

Table 5.3: Would you be able to use the standard to make life better?

	Frequency	%
Base	113	
I would understand better what support I should expect to receive	69	61%
I would understand how staff should be working to support me	63	56%
I would feel more confident to ask for what I need	62	55%
I would be able to express concern if my care did not meet the standard	63	56%
I could represent other people with dementia and carers in improving services	45	40%
Not sure	9	8%

Suggestions made by people affected by dementia within open questions, or during the qualitative exercises, as to how they would use the standard included:

- To underpin complaints
- To encourage discussion.

“The guidelines are probably most useful in encouraging a discussion between care providers and users of what actually works – and why, despite best intentions, some aspirations... are not being received [by people with dementia and carers].

- Carer, survey respondent

The extent to which people felt able to use the standard would depend upon:

- People knowing who to approach if the standard is not being met/ enforcement/ regulation
- The extent to which the standard could be seen as clearly specifying what needs to be provided and what rights people have
- Staff skills
- Empowerment
- Receptivity to complaints against services
- Effective dissemination, including by word of mouth.

“It could [make life better], if we can use it as a standard, with the provisos we have said today and providing it has teeth. For us as carers to have statements like this it is really useful to empower us.”

- Carer, focus group attendee

“I would like this standard to be underpinned by the European Convention on Human Rights and I would like our rights to be made explicit.”

- Person with dementia, survey respondent

“To help me it would need to include information about who to contact - all too vague at present.”

- Person with dementia, survey respondent

Challenges in implementing the standard

Several key challenges were identified in relation to implementing the standard.

Implementation in a time of austerity

Consultees from all groups felt that the standard is a challenge to current practice (see Chapter 3 above), and that therefore there is a need to raise the quality of dementia care delivered. Raising quality without increasing resources is clearly a challenge and this was acknowledged by many consultees. Some people felt there was an existing ‘postcode lottery’ in terms of the quality and quantity of provision and it was not clear how the standard might overcome this.

“It’s all very well having these quality standards but who is going to do all these things and where is the money going to come from? Services are being cut. There was a good befriending service in our area and the money has been withdrawn by the local authority so people can only have the service if they pay. It’s not the sort of thing that would be at the top of people’s list of essentials.”

- Person with dementia, interviewee

“The lack of resources – services are in crisis. There is a big gap in what we’d like to see and what people experience.”

- Representative body

Bringing the standard to life

Consultees acknowledged that the standard may have the potential to be a 'box ticking exercise' and some were embittered by previous experience.

"This smacks of covering your backs, getting more and more piles of paperwork that has little to do with giving real practical help for carers of people with dementia."

- Survey respondent, carer

It was also acknowledged that expectations would need to be managed, otherwise the experience of implementation could lead to further disappointment, raising 'false hope' and breakdown of relationships between service providers and users. Conversely, raising expectations could also be seen as a challenge if the standard is to be used effectively to improve services. Awareness raising would need to be tackled.

"I think people need to know what the standards are first in terms of their expectations because I think there are a lot of people out there with low expectations and unless they know about the standard and what they should be expecting then they can't challenge the system."

- Staff member, focus group attendee

Enforcing and measuring the standards

Other key challenges include how to enforce the standards:

"It doesn't have targets and timescales so I'm not sure how in practice it will shift what people are doing."

- Representative body

And, how to effectively measure them:

"Sometimes what we find is that some of the ways of measuring these kinds of statements aren't necessarily appropriate for people with dementia. So sometimes when we are told to measure things in a certain way, using a particular tool, we struggle to make it relevant to people with dementia. It's one of the main reasons why I've suggested that I'd like to see more specific guidance on what methods of evaluation are appropriate for people with dementia because there is a lot of limited knowledge about the difficulties involved in consulting people with dementia."

- Representative body

Overcoming challenges

Workforce development was a key theme that emerged in the discussions about how to overcome the challenges anticipated by participants in relation to implementing the standard.

“As well as raising awareness, there is a need to train people across social care and broader services to know what the standard means for them.”

- Staff member, focus group attendee

“Its almost like we need to map existing training in this area to find out that there is training available to meet the training needs outlined in the standard.”

- Staff member, focus group attendee

Integrated working was also seen as important (in particular between health and social care, but also other services such as leisure and community development):

“Because that is a lot of the daily difficulty, knowing who to talk to about certain things because what is health and what is social [care], what is funded and what is not, and are you asking the wrong person because they don’t want to fund it... We would like everything to be joined up. Wherever you go you get access to everything else. We don’t care who does it, so long as we get the desired result.”

- Carer, focus group attendee

Other suggestions included those in the table below.

Table 5.4: Further suggestions on overcoming challenges

Suggestion	Comments/ examples
<p>Guidance and case studies – there was clear support for this type of resource throughout the focus groups</p>	<ul style="list-style-type: none"> ▪ Additional guidance on how to use the standard, some issues that might be faced and some examples of how others have overcome the issues in real life. ▪ Sharing of good practice that already exists, or is currently being generated, including cross-disciplinary learning ▪ Making it Real case studies ▪ Developing appropriate tools for use in evaluating standards amongst people with dementia ▪ Organisation-specific internal guidance ▪ Literature from representative bodies

Suggestion	Comments/ examples
Raising awareness in the community	<p><i>“A lot of the work that we do involves both the local community and people who have dementia so that you can increase understanding and help people living with dementia make a contribution. For example, local tea dance is for everyone. The joy is that people who don’t have dementia come into contact with people who have dementia as quite often the wider community can be frightened by people with dementia.”</i></p> <p>- Staff member, interviewee</p>
Cross referencing the standard with other policy	<p><i>“There is another document Progress for Providers for Dementia and in an appendix, they cross reference each of their standards with the Making it Real standards... A lot of providers that I’ve been talking to say that when they see standards cross referenced that they breathe a sigh of relief as they don’t have to do that work as someone has already done for them.”</i></p> <p>- Representative body</p>
Funding and support	This was linked to resources issue listed above and a feeling that improving quality would require additional resourcing.
Creative approach	Including partnership working and use of volunteers
Role for leaders in implementation – champions as well as leaders	<ul style="list-style-type: none"> ▪ Possible role for national lead body on dementia ▪ Need for leaders to be identified within organisations
Links to other initiatives	<ul style="list-style-type: none"> ▪ Dementia Friendly Communities ▪ Innovations in Dementia
Timely provision of information.	Need to make sure that people have access to the right information at the right time for them. Good practice example: representatives from Alzheimer’s Society attended memory clinics so they were on hand to give information when individuals needed and wanted that information.

Support needed for implementation

Interestingly, similar proportions of people affected by dementia (80.7%) and staff (83%) felt they would need support to use the standard.

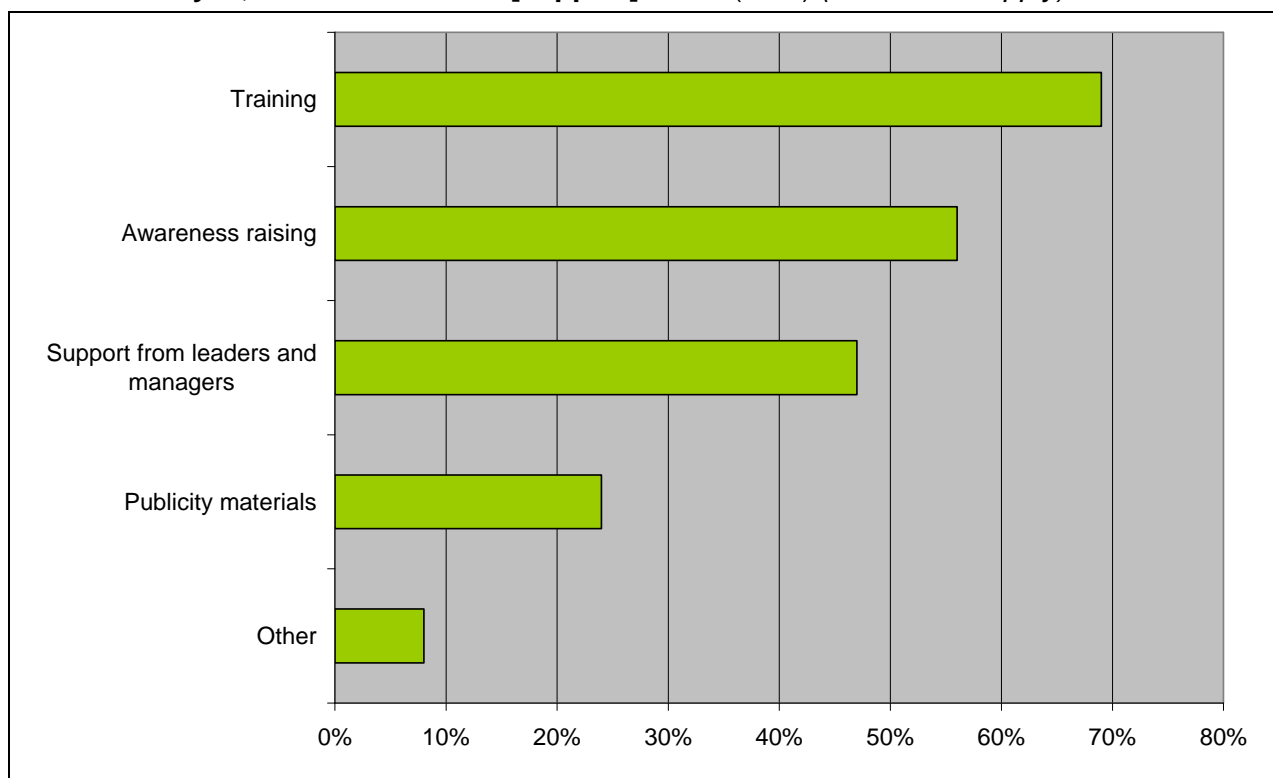
Table 5.4: Do you feel that people with dementia and their carers will need support to use this standard / support will be required to assist practitioners in your setting implement the quality standard?

Response	Staff		People affected by dementia	
	Frequency	%	Frequency	%
Base	88	100.0%	109	100.0%
Yes	73	83.0%	88	80.7%
No	4	4.5%	2	1.8%
Not sure	11	12.5%	19	17.4%
Not applicable	2	*	0	*
No response	10	*	4	*

Support for staff

Training was most commonly suggested by staff as the method of support that would assist in implementation.

Table 5.5: If yes, what form should [support] take? (Staff) (Tick all that apply)



N=100.

The importance of ensuring that people living with dementia and carers are aware of the standard and clear about expectations from health and social care services was highlighted. However, there was a concern raised that if awareness of the standard was raised, along with

expectations, service users might face disappointment as their expectations might not be met in the face of service cut backs.

One staff interviewee commented on the fact that the standard wasn't compulsory and while they did not advocate that the standard should be made compulsory, there was some concern expressed in relation to how it was going to be taken seriously.

The option for specific awareness-raising activities (e.g. training sessions, media work) for families and individuals living with dementia was suggested, while the need to make carers and people with dementia more aware of services available more generally was also highlighted.

From a service providers' perspective, interviewees indicated that guidance and training could be developed to raise awareness among practitioners perhaps supported by examples of good practice or case studies. This way the document would be brought to life rather than something that isn't used on a day-to-day basis. The Making It Real approach was quoted as a positive way of developing case studies and showing how the standard can be used to improve practice. Other suggestions included using people who live with dementia to deliver training to staff in order to address some stereotypes and stigma associated with dementia.

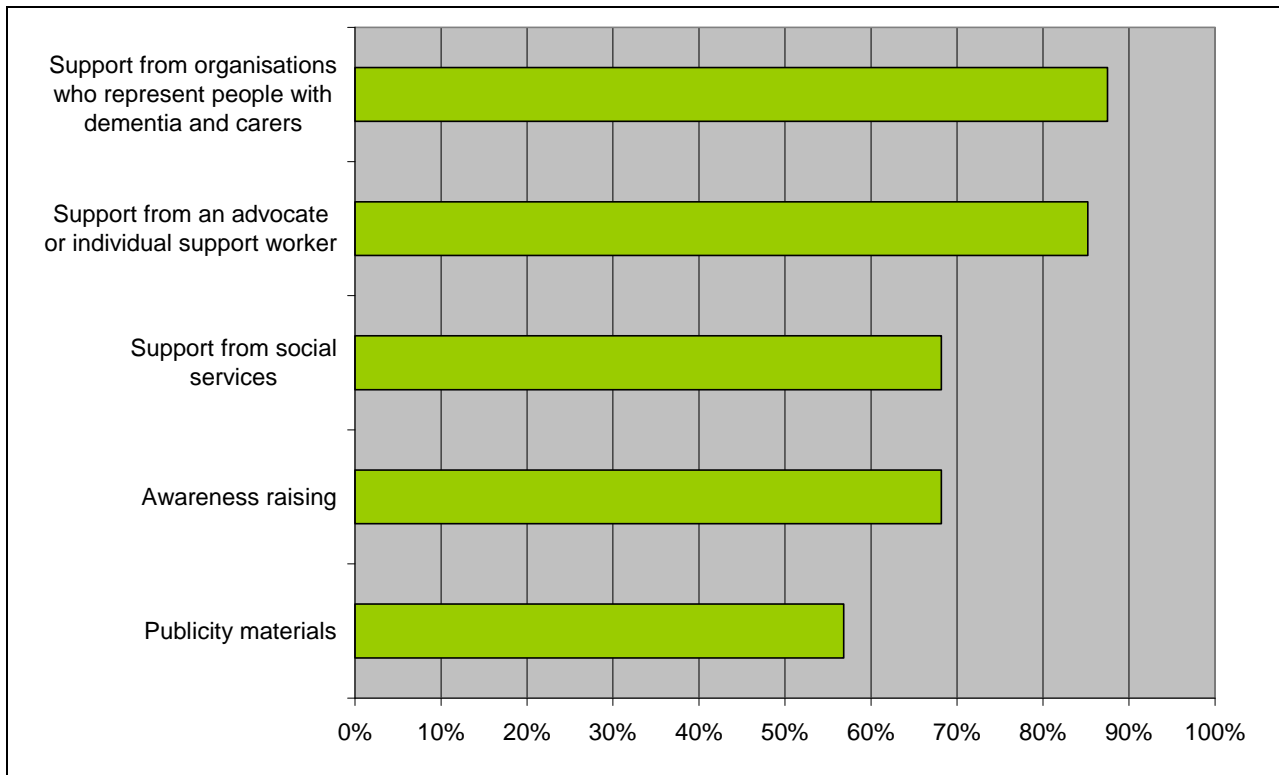
There was a view that the standard needed to sit within the broader context of government policy and that it would be impossible to use it in isolation from the wider healthcare and access issues.

Support for people affected by dementia

Among people with dementia and carers, support from representative organisations was the most popular method of support, closely followed by support from an advocate or support worker.

There was a sense that it would be useful for service users to know about the standard and comments from the qualitative exercises tended to focus on awareness raising rather than support to use the standard as a first step. Two main suggestions emerged from the qualitative data: the use of community based networks to promote and disseminate; and, potential for group work to raise awareness of the standard.

Table 5.6: If yes, which of the following types of support would you agree with? (People affected by dementia) (Tick all that apply)



N=88.

The use of existing community-based organisations, for example, Age UK, GP surgeries, patient participation groups, social service staff all would be good routes to promote the standard:

“Information at GP surgeries, in their waiting rooms...places where people are likely to come into contact with information.”

- Carer, interviewee

Interviewees reflecting on the Asian community in particular were clear that this was a potential route through which the standard could be promoted. There were two reasons given for this. First on a practical level community groups could help with translation of the standard if that was needed. Second reflects the need for trust to be established before introducing the standard or expecting a response to the standard. Community groups already have existing relationships with members from the local community. By working through these organisations, the standard would benefit from this relationship and potentially increase response to the standard.

A small number of respondents suggested some group work to develop awareness and importantly understanding of the standard. The concept of a few people working together to look at each statement and how that might relate to their situation was floated, accepting that different statements would be more relevant to some than others. This could include people outside the family who provide care as well as family members.

Summary

Staff provided many examples of how they felt the standard could be used in practice, to support dementia care quality and drive up standards. For people with dementia and carers, the key uses of the standard would be to help challenge services, get involved in discussions around service provision and to underpin complaints. The extent to which this would be possible would depend upon the extent to which the standard is made accessible to these groups, and groups feel empowered to use it.

There was some concern expressed by field testing participants that resource constraints could limit the ability of the standard to drive up quality, and/or that the standard would need to be enforced to ensure compliance. Integrated working between health and social care was seen as key to successful implementation of the standard, as was workforce development. Guidance and training for social care staff were recommended to support implementation; and people with dementia and carers felt that support from representative organisations, advocates and staff would be important to enable them to utilise the standard.

Overall it could be said that concern was raised during the field testing that implementation of the standard will really be key to its success. Many detailed examples were given of how it might be implemented in practice, but there was a feeling that the standard in itself, as a document published and disseminated, may not achieve what it sets out to do without a wider programme of support around it. This view was common and could perhaps be summed up by one consultee from a representative body:

"I think it is helpful but it won't go very far. It is admirable in its breadth but I'm aware that NICE already have some guidance around dementia and I'm not sure that has been that successful in driving standards up on its own. It needs to be clearer exactly how it hopes to drive standards up. The process of implementation is a concern."

- Representative body

6. Findings – equality issues relating to the standard

The qualitative exercises explored issues around the equality and diversity impact of the standard.

Extent to which standard is currently inclusive

Views of people affected by dementia

From the interviews undertaken with people living with dementia and their carers, there were different opinions as to whether the standard was inclusive and would be helpful for everyone.

At least half of those interviewed felt that the language used and the approach taken in the standard was inclusive. There was some recognition of the ‘general’ nature of the standard meant it could be inclusive and there was scope to tailor the standards and respond to the concerns of different populations at a local level. One interviewee did point out however that the standard could be more explicit about the need for inclusivity and be clear about the importance of meeting the needs of different groups.

“It needs to be explicit in the statement that inclusivity is key, that differences must be met.”

- Carer, interviewee

On a broader note, there was clear acknowledgement that people living with dementia are a diverse group. For example the stereotype of dementia being an old age condition was one they felt should be challenged. While this was a comment on the perception of dementia per se rather than the standard itself, it was a strong sentiment expressed by people living with dementia and their carers.

Only one interviewee did feel that the standard could not really be helpful for everyone as everyone is different. Finally one interviewee felt the wording could be improved but wasn’t able to give suggestions for improvement.

Views of the workforce

At least half of those interviewed felt the standard was inclusive and recognised the value of general language in a document of this nature. One interviewee commented that the standard talks about individuals and their needs and in this way it covers everyone.

A significant number of interviewees were concerned about broader factors around equality including cultural norms in relation to recognising dementia, seeking help and accepting support. There was a sense that some sections were not accessing health, social care or voluntary sector support and there was an opportunity to be more proactive to encourage contact with services.

On the other side, cultural awareness among staff to recognise the issues facing some members of the community was identified as important.

There was also awareness that, regardless of how inclusive the standard might be, implementation would be key to any impact on equality.

“The language is there in the standard and statements, so really it’s down to how they are implemented in practice.”

- Representative body

Needs of specific communities

LGBT community

One interviewee pointed out some of the difficulties associated with the standard for the lesbian, gay, bisexual and transgender community (LGBT). There was a feeling that the standard, and in particular statement 9 was reflecting traditional views that a family or relationship involved husband, wife and loving family. For the LGBT community this is not the case and some reflection of this diversion from this understanding of family was needed. The interviewee went on to describe the wider social context where often LGBT people with dementia were not accepted in a holistic way and often went ‘back into the closet’. While the wording of the statement was accepted, there was a sense that the associated definitions would need tightening e.g. what does ‘community’ mean for different groups of people.

Minority ethnic communities

Continuing with this theme, a number of interviewees pointed out that regardless of how inclusive the standard was, that the stigma associated with having dementia within the Asian community makes it difficult to access support through social care services. This cultural perspective is an issue for implementation of the standard although there was a suggestion that reflecting the standard in practice and considering how users might experience the service might be more important than encouraging individuals to use the standard themselves.

A significant number of staff interviewed were also concerned about broader factors around equality including cultural norms in relation to recognising dementia, seeking help and accepting support. There was a sense that some sections weren’t accessing health, social care or

voluntary sector support and there was an opportunity to be more proactive to encourage contact with services.

Learning disability

Some members of the workforce were concerned with the underlying assumption evident within the standard that people with dementia would be part of a 'traditional' family and network of friends. In particular, people with learning disabilities may not be living at home when they develop dementia, may not have the same life experiences to fall back on or the same structure of family and friends to advocate on their behalf. Under these circumstances, the importance of paid carers should not be underplayed as they might well be the people who know the individual best.

"It's not treating people who are already in the care sector who develop dementia so by saying the carers are unpaid people – well we just don't have these types of carers ...we [paid carers] need to have the input on their behalf."

- Social care worker, specialist provision

It was also requested that an EasyRead version of the standard be produced for people with learning difficulties and disabilities.

Mitigation of uneven impacts

There were few suggestions as to how the standard could be improved to mitigate against uneven impacts felt by the different groups. However, there was some support for guidance associated with the standard that could consider how individual statement related to minority groups, for example LGBT, people with learning disabilities.

"It's where you do need a guidance document to support the standard where you can take each statement and say from the inclusion perspective 'here is what you need to do'."

- Representative body

With particular reference to the issues facing people without a family network, there was the suggestion that the word 'carer' needs some more consideration. In some instances this will have to include a paid employee as the person who cares for individuals the most and often act as an advocate. This should be reflected in the standard but also any guidance produced.

There was some discussion around the importance of cultural and faith systems and how this might be reflected through the standard. One option put forward was to consider this in the context of a human rights agenda.

One staff interviewee pointed out that it would be important to continue to ensure the needs of different communities were being met through any monitoring data collected. In order to do this it would be essential to consider data from minority groups separately to ensure their voice is not lost.

Finally, one specific comment related to a point on page 27 of the draft standard where it states that people should have an interpreter or advocate. To the reader this might be unclear if this is due to the condition or because English is not the first language. The interviewee (a member of the workforce) felt this ambiguity should be addressed.

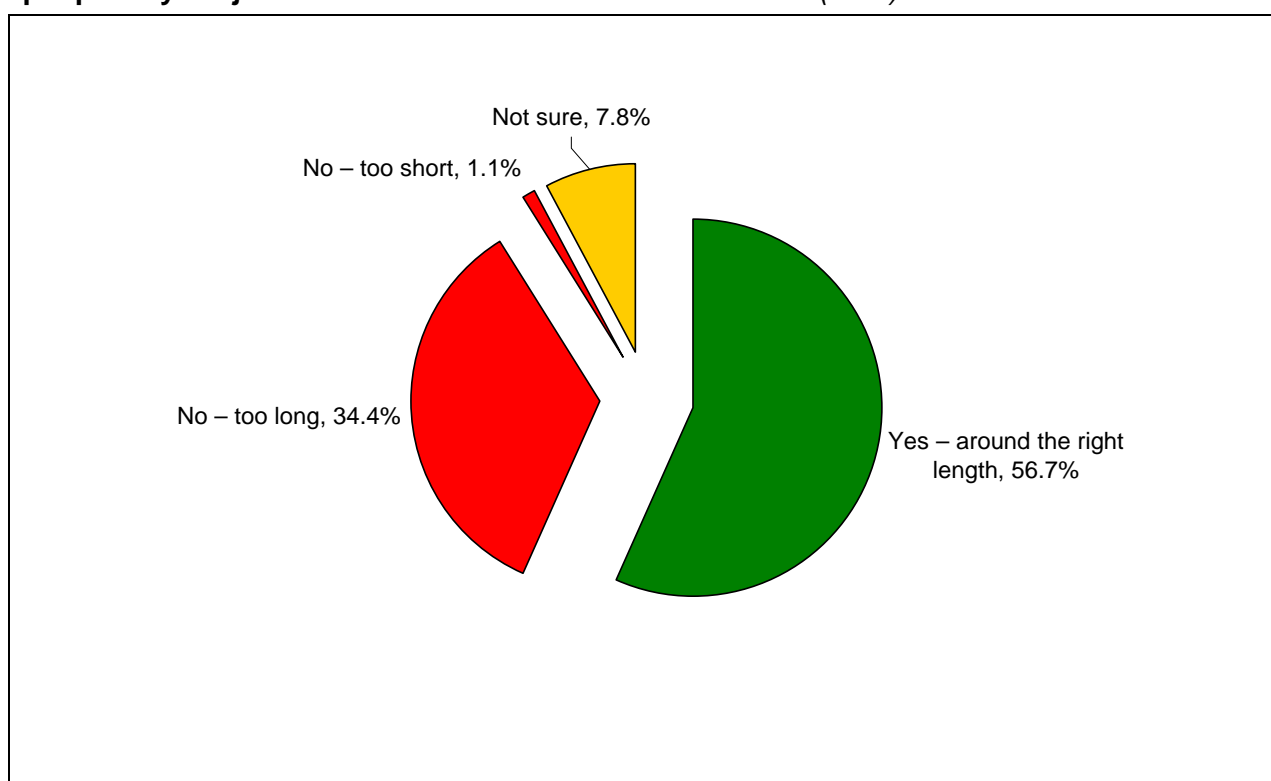
Summary

The issues of equality impact was explored within the qualitative exercises. There was a mixed view from participants, 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.

7. Findings – dissemination

More than half of staff who responded to the survey thought the standard was of the right length (56.7%), though a significant proportion (just over a third, 34.4%) felt it was too long. Only 1.1% felt it was too short. There were no significant differences in response by job role, but looking at sector breakdowns, local authority respondents were significantly more likely to consider the standard as of the right length, than health sector respondents, who were more likely to feel it was too long.

Table 7.1: Do you think that the length of the standard is appropriate to encourage people in your job role to read and absorb the contents? (Staff)



N=90. Excludes 10 non respondents.

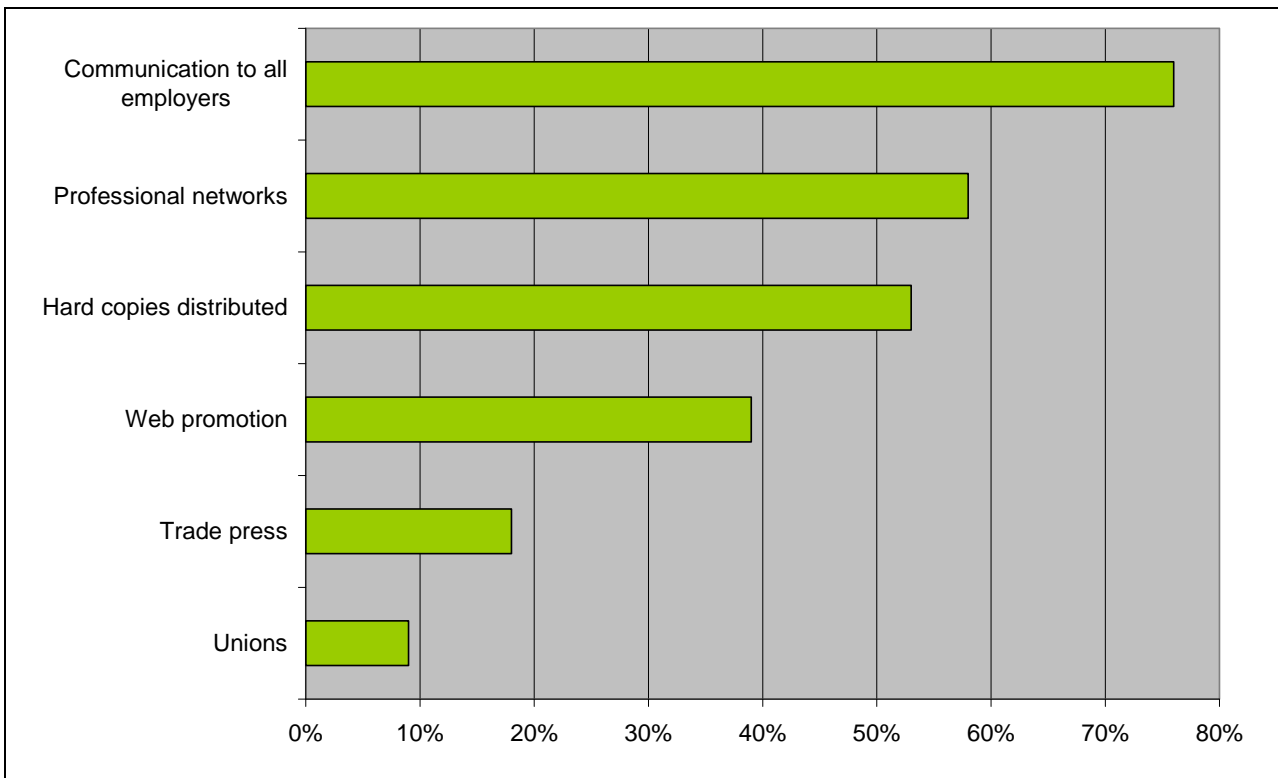
Staff responding to the survey were also asked about the method of dissemination. The most popular method was via a communication to all social care employers.

People with dementia, carers and professionals involved in the qualitative exercises were asked about the best way to disseminate the standards. Common suggestions included dissemination via:

- Networks new and existing, including a good practice forum / website to share learning and resources
- Training and competency
- A guide

- Links to other standards
- Competency after training also needs to be managed – supervision and appraisal
- Dementia Champions
- Link with commissioners
- Media campaigns
- Qualifications, badges and awards
- Promotion via health staff and copies in appropriate places, e.g. doctor’s surgery
- Learning appropriate to different learning styles
- Briefings and roadshows
- Videoclips, social media and newsletters.

Table 7.2: How should the Quality Standard be disseminated to dementia care professionals in your type of setting? (Staff) (Tick all that apply)



N=100

Raising awareness of the document was seen as key to support use of the quality standard: *“It needs to be a live useful document rather than something that’s used by commissioners once a year.”*

It was commented that training for social care staff could be led by carers and people with dementia: *“Having experience of this, it’s far more powerful than many other approaches as you get to the heart of the issue. It’s really easy to write people off with dementia and there is such a range of ability and memory so it’s very easy for staff to write them off so if first trainings programme involved people with dementia that might help change attitudes and shift the culture.”*

There also may be a particular need to ensure that self-funders, who have limited access to services, will be empowered to use the standard. While the standard itself was seen as empowering, discussion around empowering or enabling people usually referred to support for implementation, such as resourcing to underpin the statements or a role for advocates, advisers and the paid workforce.

8. Conclusions and recommendations

The field testing has demonstrated that there is a high degree of support for the dementia social care standard, both among social care staff and among people affected by dementia. Although many people are sceptical and some pessimistic about the potential for change, most consultees felt that the standard was suitably aspirational, and if implemented, would improve quality of services above their current level.

Implementation itself however was deemed to be problematic by many participants in the field testing. Consultees were unclear about the framework within which the standard will operate and the processes and activities which will bring it to life. Most people felt that both practitioners and people affected by dementia would need support to understand the standard and to implement it. This support might take the form of workforce development, active dissemination, support from representative organisations and advocacy. There was a concern that in the current financial climate, the measures required to genuinely implement the standard and achieve aspirations would not be resourced, leading to disappointment.

It is therefore a recommendation of this report that dissemination of the standard is accompanied by a clear explanation of how the standard will be implemented, including discussion of the role of NICE *vis a vis* other stakeholders. NICE may wish to explore, via the TEG or other networks, whether a covenant can be agreed upon with other stakeholder organisations to take responsibility for delivering specific activities around dissemination and implementation to ensure the standard does not stand in isolation.

“It needs to be communicated to the general public in such a way that it is accessible. At the moment it is not. If it is presented as rights, you are going to get a flood of people defending their budgets as people demand rights. If it is framed as aspirations, things we want to achieve, we could all work together to make them happen.”

- Carer, focus group attendee

Important discussions around equality and diversity also emerged during the field testing, that suggested that people with dementia and carers from minority groups do 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.

Overall, participants in the field testing felt that the statements in the standard were clear. Many statement-specific suggestions were given for improvement; these were described in detail in Chapter 6 and NICE will want to review these in detail.

Points that were made that were relevant to all statements included:

- a need to check for jargon and define terms throughout (an improved glossary may be helpful, and headline statement should avoid difficult vocabulary, since readers will not always want to turn to the glossary)
- it may be appropriate to define that “carer” means an unpaid carer, e.g. family or friend, rather than professional
- it may be appropriate to include carers in some or all of the statements where they do not currently appear (whilst acknowledging that not all people with dementia have the support of a carer)
- often, integration between health and social care (and sometimes other stakeholders) will be key to realising the aspiration of the statements
- there is a need generally, to be clearer about the ‘who, what, when’ in statements, but in particular ‘who will be responsible’.

NICE may wish to review the wording of the statements and other parts of the standard to ensure that the active voice is used wherever possible, to assist readers in understanding ‘who is responsible’ and reassure them that there is a thread of accountability running through the document.

Finally, many useful suggestions for dissemination were received from both the workforce and those affected by dementia, including active dissemination through employer networks and representative organisations. An EasyRead version of the standard was suggested for all lay people and NICE may wish to produce copies in common languages other than English, for example Urdu, Gujarati, Arabic and Bengali.

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