

Quality Standards Care of people with dementia TEG 3 Day 1

Minutes of the meeting held on Monday 19th November 2012 at the NICE offices in Manchester

Attendees	<p><u>Topic Expert Group (TEG) members</u> David Croisdale-Appleby [chair] (DCA), Alisoun Milne (AM), Allison Cowley (AC), Catherine Pascoe (CP), Gill Boston (GB), Graham Stokes (GS), Jakki Cowley (JCo), James Cross (JCr), Jane McKeown (JM), Jennifer Wenborn (JWe), Mary Moss (MM), Sarah Carr (SC), Sharon Blackburn (SB), Simon Williams (SW), Tim Sanders (TS), Victoria Metcalfe (VM), Wendy Neil (WN)</p> <p><u>NICE Staff</u> Brian Bennett (BB), Craig Grime (CG), Daniel Sutcliffe (DS), Jane Silvester (JSi) [am only], Lorraine Taylor (LT), Nick Staples (NS)</p> <p><u>Field testing team [am only]</u> From Skills for Care: Jenny Swift (JSw), Karen Stevens (KS), Paul Buchanan (PB) From Dementia UK: Joy Watkins (JWa)</p> <p><u>Observers (NICE Staff)</u> Anne-Louise Clayton [pm only], Edgar Masanga, Marisa Dias</p> <p><u>Observers (NICE Social Care Fellows)</u> Colin Angel, Julia Scott, Maureen Ray</p>
Apologies	<p><u>TEG members</u> Ken Clasper (KC), Jean Hannah (JH)</p>

Agenda item	Discussions and decisions	Actions
<p>1a. Introductions, apologies and minutes from the last meeting</p>	<p>DCA welcomed the attendees and reviewed the agenda for the two days. Members of the Topic Expert Group (TEG) and the field testing team introduced themselves. JS was introduced to the TEG.</p> <p>DCA informed the group of the apologies received from TEG members unable to attend.</p> <p>The group agreed the minutes from the TEG2 meeting held on 15th and 16th May 2012. At both the TEG 2 and TEG 3 meetings there was a discussion about the new extended remit for NICE into social care and the procurement process for the NICE Collaborating Centre for Social Care. In particular, there was a discussion about the need for a tendering process. It was explained that all NICE's collaborating centres for guidance production are all procured through a formal tender process, as a legal requirement.</p>	
<p>1b. Declarations of interest</p>	<p>DCA asked the group whether they had any new interests to declare since the last meeting. The following TEG members declared interests:</p> <ul style="list-style-type: none"> • GB noted that she has been appointed as public/lay person on a Clinical Commissioning Group • AM noted that she has been appointed as a peer reviewer for the Social Research Council • SC noted that she is an employee of SCIE, which is bidding to host the NICE Collaborating Centre for Social Care. • DCA noted that he is named as a partner in the bid for SCIE to host the NICE Collaborating Centre for Social Care. 	
<p>2. Communications and Dissemination Strategy</p>	<p>SW gave a brief presentation on the draft dissemination strategy as circulated in advance to the TEG.</p> <p>The TEG asked whether input was needed from them on building a question and answer briefing. SW outlined that he would be seeking the TEG's input. The TEG noted that a major issue would be the handling of the positioning of the published quality standard alongside this quality standard. SW noted that the NICE team was looking at options on how best to communicate and align the products.</p> <p>SW asked the TEG to consider any feedback they may have on his paper. The TEG provided a number of examples of organisations that NICE could use as dissemination partners and agreed to feedback to Simon after the TEG meeting.</p>	<p>Action 1: NS to seek feedback from the TEG on SW's paper and collate this before sending to SW.</p>

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	<p>The TEG asked about shared learning and good practice examples, as well as education and training.</p> <p>SW noted that a NICE Shared Learning database exists that is hosted by implementation. JCr noted that the quality standard would be picked up by Skills for Care in future training packages.</p> <p>DCA thanked SW for his contribution.</p>	
<p>3. Presentation of findings from field testing</p>	<p>JSw and JW presented the findings of the field testing. Following the presentation, the TEG was given the opportunity to ask questions. JSw, JW, KS and PB responded to queries.</p> <p>The TEG noted that the QS had been seen as challenging to current practice, but noted the importance of reducing jargon and ensuring that the QS was specific enough to lead to change in practice.</p> <p>The TEG queried whether the perspectives of people with advanced dementia had been captured. The field testing team noted that this was a difficult area to capture, but that views that were partly representing this group were gained through eliciting the responses of family carers.</p> <p>The TEG queried whether building design had been discussed. The team noted that there was some discussion on this in the learning disabilities focus group.</p> <p>The TEG queried the meaning of the term “early stages”. The team noted that this was not referring to early onset dementia but meant the early stages of dementia. It was noted that not all participants wanted to discuss end of life care at an early stage, but all wanted the possibility of a discussion.</p> <p>The TEG asked about whether the carer or person with dementia would benefit from having the QS. The team noted that the findings show that it provides more information which would help especially carers finding out about what they can access. The TEG queried whether the QS needed to be made available more widely. The team noted that the findings suggest that a short version on hand or available in communal community locations such as doctors’ surgeries would be helpful.</p> <p>The TEG queried whether there was dissonance between carers and people with dementia. The team noted that there were queries around confidentiality and people not wanting additional care from outside of the family</p> <p>The TEG queried whether the existing QS had been discussed in terms of its use in the system. The team</p>	

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	<p>noted that the workforce were aware of it, and felt it hadn't improved quality. The team noted that the more empowered people with dementia and their carers had used it and found it helpful.</p> <p>The TEG noted some discussions around specific changes to statements that would be picked up in the statement-by-statement discussion later in the day.</p> <p>The TEG queried who the front line non-residential workforce consisted, i.e. whether these were providers or commissioners. The team noted that 3 in this group were directly providing services, with 2 commissioning.</p> <p>The TEG asked whether there had been discussion around the published and new quality standard. The team noted that the general view was that the two QS should be brought together. The TEG strongly supported the need to bring together the two QS.</p> <p>The TEG asked whether advocacy was supported by the field testing. The team noted that it was seen as important, but that in the area in which this was discussed, the advocacy service had been abolished and this therefore they were unsure how to ensure their clients received independent advocacy, noting that paid staff could not be independent in terms of advocacy provision for their clients.</p> <p>The TEG queried the future implementation of the QS and the need for local case studies and good practice to underpin the implementation of the QS. The team noted that there was a strong request for local knowledge to drive improvement.</p> <p>The TEG queried whether existing rights and eligibility criteria could be signposted in supporting documentation. The NICE team agreed to discuss this and suggested raising this with the implementation team on Day 2.</p> <p>The TEG queried whether the field testing had brought out any omissions. The team noted that nothing specific had come up however identification of omissions was not in their specific remit.</p> <p>The TEG noted the importance of ensuring that if the QSs are used in commissioning, that the outcomes and not the process are the focus.</p> <p>The TEG noted a discussion point on the use of the passive voice. The NICE team agreed that this would be explored with the editorial team.</p>	

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	DCA thanked the research team for their work.	
4. Presentation and discussion of consultation feedback	<p>LT presented a brief summary and outline of draft quality standard consultation feedback. CG reminded the TEG that in regard to the integration of the QSSs, the TEG needed to ensure that existing statements are not duplicated. CG also highlighted that the TEG would need to consider the consultation feedback around the distinction between the carer and the person living with dementia.</p> <p>The TEG noted that the QS was not just focussing on local authority provision/commissioning, but also about communities and individuals who fund their own care.</p>	
5. Presentation, discussion and agreement of final statements (including equality impact assessment)	<p>CG gave a presentation to outline the plan for the afternoon and next day. CG also noted the importance of ensuring that statements are precise and concise.</p> <p>CG presented feedback from the consultation and referenced the field testing report by going through each statement in turn.</p> <p>The TEG considered draft quality statements 1 to 3 as outlined in the consultation version of the draft quality standard alongside stakeholder comments and the field testing report.</p> <p>The TEG agreed to consider progressing draft quality statements 1 to 3 to final quality standard with some amendments.</p>	
6. Summary of the day and plan for tomorrow	DCA thanked the TEG for their work and asked the TEG to take the opportunity to re-review papers ahead of the second day.	

Quality Standards Care of people with dementia TEG 3 Day 2

Minutes of the meeting held on Tuesday 20th November 2012 at the NICE offices in Manchester

Attendees	<p><u>Topic Expert Group (TEG) members</u> David Croisdale-Appleby [chair] (DCA), Alisoun Milne (AM), Allison Cowley (AC), Catherine Pascoe (CP), Gill Boston (GB), Graham Stokes (GS), Jakki Cowley (JCo), James Cross (JCr), Jennifer Wenborn (JWe), Mary Moss (MM), Sarah Carr (SC), Sharon Blackburn (SB), Simon Williams (SW), Tim Sanders (TS), Victoria Metcalfe (VM), Wendy Neil (WN)</p> <p><u>NICE Staff</u> Brian Bennett (BB), Craig Grime (CG), Daniel Sutcliffe (DS), Jane Silvester (JSi) [pm only], Lorraine Taylor (LT), Nick Staples (NS)</p> <p><u>Observers (NICE Staff)</u> Alexa Biesty, Anne-Louise Clayton, Christina McArthur</p> <p><u>Observers (NICE Social Care Fellows)</u> Julia Scott [am only], Maureen Ray</p>
Apologies	<p><u>TEG members</u> Ken Clasper (KC), Jane McKeown (JMc), Jean Hannah (JH)</p>

Agenda item	Discussions and decisions	Actions
7. Welcome and plan for the day	DCA welcomed the TEG members back for the second day and outlined the plan for the day.	
8. Presentation, discussion and agreement of final statements (including equality impact assessment)	<p>The TEG considered draft quality statements 4 to 13 as outlined in the consultation version of the draft quality standard alongside stakeholder comments and the field testing report.</p> <p>The TEG agreed to consider progressing draft quality statements 4, 6 and 8 to 13 to final quality standard with some amendments to wording.</p> <p>The TEG agreed to remove draft quality statements 5 and 7 as they duplicated the already existing quality standard.</p> <p>The TEG noted that a quality standard on carers should be commissioned and asked NICE to discuss this with the Department of Health.</p>	Action 2: NICE to discuss with the Department of Health whether a QS on carers could be considered for referral.
9. Summary of final statements	<p>The TEG was asked to consider the full set of amended statements.</p> <p>The TEG agreed to merge draft quality statements 1 and 2. The TEG agreed to progress all remaining statements to final quality standard with some amendments.</p> <p>The TEG agreed to add a statement on daily living activities to reflect consultation comments.</p>	
10. Summary of Equality Impact Assessment	The TEG agreed that they would consider any further equalities issues when reviewing the final quality standard.	
11. Next steps	LT provided an update on the next steps in the process and asked the TEG to consider if any additional organisations should be asked to endorse the quality standard and let NICE know of these organisations by email.	Action 3: TEG members to contact NS with other endorsement organisations to target.
12. Support for Commissioners and others	AB and CMc presented an update on the planned costing, commissioning and implementation work. They noted that they would be seeking input from the TEG at a later date.	

using the quality standard	The TEG asked for feedback on how the QS would be used by the social care system. JS noted that discussions with the DH and CQC were ongoing and that a position statement was being produced.	
AOB	<p>The TEG noted that the pilot of the dementia care audit at the DH was ongoing and seemed to be moving ahead of the work being done by the dementia TEG. The NICE team noted that dialogue with the DH is ongoing and is being led by the Implementation team.</p> <p>DCA thanked the TEG, the team and LT. The TEG thanked DCA.</p>	