

Quality standards advisory committee 3 meeting

Dementia (update) –review of stakeholder feedback

Date: Wednesday 20 March 2019

Minutes: Confirmed

Location: NICE office, Level 1a City Tower, Piccadilly Plaza, Manchester, M1 4TD

Attendees

Quality standards advisory committee 3 standing members:

Hugh McIntyre (Chair), Jim Stephenson (vice-chair), Deryn Bishop, Amanda de la Motte, Nadim Fazlani, Keith Lowe, Ann Nevinson, David Pugh, Darryl Thompson, Julia Thompson, Phil Taverner, Jane Dalton

Specialist committee members:

Kevin Minier, Emma Vardy, Linda Clare, Mehran Javeed, Carol Duff, Richard Clibbens, Pauline Shaw

NICE staff

Nick Baillie (1-6), Stacy Wilkinson (1-6), Laura Worthington (1-6)

NICE observers

Leanne Wakefield, Sarah Scott

Apologies: Nicola Greenway (NICE), Ivan Benett, Malcolm Fisk, Madhavan Krishnaswamy, Gary Bickerstaffe (SCM), Chris Roberts (SCM), Tracy Wright (SCM)

1. Welcome, introductions objectives of the meeting

The Chair welcomed the attendees and the quality standards advisory committee (QSAC) members introduced themselves. The Chair informed the committee of the apologies and outlined the objectives of the meeting, which was to review stakeholder comments on the Dementia (update) quality standard.

The Chair welcomed the public observers and reminded them of the code of conduct that they were required to follow.

2. Confirmation of matter under discussion and declarations of interest

The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion in the morning session was the Dementia (update): specifically, the 7 quality statements included in the draft quality standard. The areas covered by the statements are:

- Prevention – health promotion
- Diagnosis
- Named care coordinator
- Activities to promote wellbeing
- Managing distress
- Advance care planning
- Supporting carers

The Chair asked standing QSAC members to declare verbally any interests that have arisen since the last meeting and all interests specifically related to the matters under discussion during the morning session. The Chair asked the specialist committee members to verbally declare all interests.

ACTION: NICE to make following adjustments to interest register;

- Ann Nevinson recently appointed to a committee of the Royal College of Optometrists.
- Emma Vardy will no longer receive a previously declared honorarium for a presentation on delirium. Remove from register.

3. Minutes from the last meeting

The committee reviewed the minutes of the last QSAC3 meeting held on Wednesday 20 February 2019. They highlighted that the following should be added;

- Suicide prevention - The committee discussed the issue of social media in relation to suicide but accepted that they are limited by what is in the guideline and therefore were unable to prioritise it as an area for quality improvement. The committee decided to wait to see what stakeholders raised at consultation.
- Physical activity - page 4, draft statement 5 ‘this statement is about travel to school. Physical activity in schools is covered by....’

ACTION: NICE to make suggested amendments to minutes.

4.1 Recap of prioritisation meeting and discussion of stakeholder feedback

SW provided a recap of the areas for quality improvement prioritised at the first QSAC meeting for potential inclusion in the Dementia (update) draft quality standard.

SW summarised the significant themes from the stakeholder comments received on the Dementia (update) draft quality standard and referred the committee to the full set of stakeholder comments provided in the papers.

The committee highlighted to NICE that they are uncomfortable with the wording on quality standards updates. The committee want it to be made clearer to stakeholders that previous quality statements are not disregarded.

ACTION: NICE to edit wording ‘no longer national priorities’ in text about updates to quality standards to be clearer about the process.

The committee recognised the level of effort stakeholders had put in to their consultation comments and the committee was unanimous in wanting to thank stakeholders.

The committee noted that diagnosis of dementia doesn’t necessarily mean lack of mental capacity, and considerations of capacity should be made for each individual in each circumstance.

ACTION: NICE to consider for each statement including a note recognising that diagnosis does not assume loss of capacity, but in some cases, this needs to be considered.

4.2 Discussion and agreement of amendments required to quality standard

<p>Draft statement 1: Adults accessing behaviour change interventions and programmes are informed that the risk of developing dementia can be reduced by making lifestyle changes.</p>	<p>The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team:</p> <p>The committee agreed the target audience for this statement is the general population.</p> <p>The committee acknowledged that the descriptors should list specifically which behaviour change interventions should be implemented for which specific risk factors if there is an evidence base to support this. The specific risk factors covered by this statement are in NG16. The committee highlighted the recent systematic review on risk factors of dementia published in the Lancet.</p> <p>The committee acknowledged not all types of dementia require an intervention.</p> <p>The committee considered listing the different types of dementia in the</p>
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	<p>supporting sections but decided against this as many people have mixed types of dementia. The committee agreed that vascular dementia and Alzheimer’s are the more amenable types of dementia to this statement.</p> <p>The committee were concerned that people may interpret this statement as being focused on physical benefits, however they consider the statement to focus on emotional benefits as well.</p> <p>The committee considered using ‘reducing risk’ or ‘delaying onset’ as an alternative phrase to ‘prevention’, as they chose not to prioritise prevention as an area for quality improvement at the prioritisation meeting.</p> <p>ACTION: NICE to remove the word ‘prevention’ from the statement title.</p>
<p>Draft statement 2: Adults with suspected dementia are referred to a specialist dementia diagnostic service.</p>	<p>The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team:</p> <p>The committee agreed that the action in this statement is not already happening and there is wide variation nationally, and therefore it should be included in the quality standard.</p> <p>The committee discussed what referral to a specialist service means, and decided not to change the current wording of the statement, as it keeps it open to different referral pathways. They agreed to add wording from the guideline definition of referral to the statement definition to clarify that specialist input is key, rather than the location.</p> <p>The committee acknowledged that families and carers are usually the ones suspecting the dementia and identifying the need to visit a GP.</p> <p>The committee recognised that there were many consultation comments on timeliness of diagnosis but pointed out that timeliness is already covered elsewhere in NHS England standards and MSNAP. They therefore agreed to leave timeliness out of the statement wording and leave it in the rationale.</p> <p>ACTION: NICE to include that families and carers should be included depending on the patient’s capacity.</p> <p>ACTION: NICE to include different subtypes of dementia in the rationale.</p> <p>ACTION: NICE to reorder rationale wording.</p> <p>ACTION: NICE to add guideline definition of ‘referral’ to be clear that it doesn’t necessarily need to take place in a clinic.</p> <p>ACTION: NICE to edit the process measure title to include ‘on to the GP practice register’.</p>
<p>Draft statement 3: Adults with dementia have a named care coordinator.</p>	<p>The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team:</p> <p>The committee confirmed that the focus of this statement is on adults diagnosed with dementia.</p>

	<p>The committee discussed the wording of the statement. They explored the use of ‘care navigator’ and concluded that whether a patient’s care is navigated or coordinated depends on the stage of the dementia. They agreed to change the statement wording to say there is someone who coordinates care, rather than a care coordinator, due to a different role being needed at different stages. The committee also wanted the audience descriptors to recognise that the person coordinating the care may be a different person at different stages of disease progression.</p> <p>The committee discussed whether the statement should focus on the care plan instead of the care coordinator. They agreed that the statement should focus on the coordinator, and that the role of the coordinator includes ensuring that there is a care plan, to match the way the guideline recommendations are set out. This is already included in the measures and other supporting sections of the statement.</p> <p>The committee highlight that this statement may have resource impact if the person coordinating the care is a health or social care professional. This is because carers as well as the person with dementia are in need of the coordination – the coordination should not fall to carers.</p> <p>The committee discussed the wording of the rationale. They agreed to add ‘vision impairment’ into the rationale alongside cardiovascular disease and other long-term conditions. They also agreed that the wording around the role of the care coordinator should be looked at, and something added about the role changing depending on the stage of dementia.</p> <p>ACTION: NICE to look at the wording around the role of the care coordinator in the rationale.</p> <p>ACTION: NICE to change the statement wording to say there is a person who coordinates care, rather than a care coordinator.</p>
<p>Draft statement 4: Adults with dementia are given a choice of activities to promote wellbeing that are tailored to their preferences.</p>	<p>The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team:</p> <p>The committee agreed that this statement applies to all dementia patients. They were clear that activities should be centred around an individual’s needs, preferences and accessibility rather than providing a standard suite of activities, as there is no evidence to show which specific activities are beneficial. They therefore agreed that the supporting sections of the statement should be changed to reflect this, and the statement should be reworded to make it sound like there is patient choice, rather than that they are ‘given a choice’.</p> <p>ACTION: NICE to amend the statement wording to reflect patient choice, for example changing it to ‘are supported to choose activities’.</p> <p>The committee discussed whether more emphasis is needed on activities being enjoyable for the individual and noted that this is already specified in the rationale, so this aspect is covered.</p> <p>The committee discussed who should commission and provide activities. They agreed that the focus of the statement is on patient choice, access and the ability to engage in them, so the details on commissioning and providing do not need to be too prescriptive and should encompass a range of activities.</p>

	<p>ACTION: NICE to make clear in the rationale that the range of options may change over time as the condition changes.</p> <p>ACTION: NICE to include family and carers in the rationale and audience descriptors.</p> <p>ACTION: NICE to consider adding a measure on access to activities, such as transport.</p> <p>ACTION: NICE to change structure measure B to 'people offering activities' instead of professionals.</p>
<p>Draft statement 5: Adults with dementia have a structured assessment before starting non-pharmacological or pharmacological treatment for distress.</p>	<p>The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team:</p> <p>The committee discussed whether the action in the statement is already being done and agreed that it needs to be included as a quality statement.</p> <p>There was discussion about safeguarding but the committee agreed that this is not the intention of this statement, so it does not need to be included.</p> <p>The committee questioned whether the statement should focus on non-pharmacological treatments before pharmacological treatments but reached an agreement that the statement focus is on doing a structured assessment at the right time. They therefore agreed to keep the statement wording but emphasise in the rationale that patients are assessed before they are treated. They explored the option to include 'managed' into the statement wording, as all symptoms are not necessarily treated for example stress is managed rather than treated.</p> <p>The committee highlighted that violence towards carers comes from stress however the guideline does not cover these concerns, and so were unable to include it in the quality statement.</p> <p>ACTION: NICE to add definition of non-pharmacological and pharmacological treatment.</p> <p>ACTION: NICE to ensure rationale focuses on doing a structured assessment before offering treatment.</p> <p>ACTION: NICE to capture the definition of distress in the rationale.</p> <p>ACTION: NICE to add families to the healthcare professional audience descriptors.</p>
<p>Draft statement 6: Adults with dementia have the opportunity to discuss advance care planning at diagnosis and at each health and social care review</p>	<p>The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team:</p> <p>The committee considered removing 'at diagnosis'. They concluded to leave it in, as they thought it was important that the opportunity to discuss advance care planning is presented to everyone at diagnosis and that the concept should be introduced early on. Committee noted that this doesn't necessarily need to be an in-depth discussion, but the opportunity should</p>

	<p>be presented.</p> <p>The committee agreed to leave the statement wording however soften the supporting information to be clear that ‘opportunities’ can mean a variety of ways.</p> <p>ACTION: NICE to review the wording of the supporting sections to make it clear that ‘the opportunity to discuss’ does not have to be a detailed conversation, and could mean giving information, for example.</p> <p>The committee recognised that there were a lot of emotive consultation comments on this statement, however the emphasis will be on having an opportunity presented at diagnosis to consider future plans, rather than to have an in-depth discussion at that time about subjects such as do not resuscitate orders.</p> <p>The committee recognised that this should be an ongoing discussion. It is not necessarily one discussion at one point in time.</p> <p>The committee noted that the quality statement should not contradict the independent review of the Mental Health Act.</p> <p>The committee agreed that the process measure should be a documented discussion at diagnosis and there can be a range of different ways of doing this.</p> <p>The committee discussed families and carers and agreed that they are already covered in the audience descriptors.</p> <p>ACTION: NICE to think about different measures, as not all of these conversations happen at diagnosis.</p>
<p>Draft statement 7: Carers of adults with dementia are offered education and skills training</p>	<p>The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team:</p> <p>The committee were comfortable with the current statement wording. They agreed that the focus of this statement is on giving relevant skills for caring rather than skills for psychological support, and therefore the rationale should focus on enabling optimal care. The second paragraph in the rationale should focus on personal wellbeing.</p> <p>The committee agreed the focus of this statement is on an informal carer becoming a skilled carer to facilitate care giving, and that this should be made clear in the rationale.</p> <p>The committee requested that time was included in the bullet point about support being tailored on page 30 of the draft quality standard because some carers will be working alongside caring. Carers may be unable to access education offered because of demand on time.</p> <p>The committee suggested the following wording, ‘carers are offered opportunities to build on education and skills,’ to avoid assuming that carers don’t already have expertise.</p> <p>ACTION: NICE to explore including recognition that carers may already have expertise in the supporting sections.</p>

	<p>The committee agreed that the process measures should not solely include carers who have had a formal assessment.</p> <p>ACTION: NICE to use the definition of carers that is in the Care Act and make it clear that this statement is focussed on informal carers and not health and social care professionals.</p> <p>ACTION: NICE to include the voluntary and third sector in the provider audience descriptors.</p> <p>ACTION: NICE to look at the wording in the rationale to check it shows that the training is about practical skills to enable care giving, as well as managing their own wellbeing.</p> <p>ACTION: NICE to add to the supporting sections that support should be provided so that carers can access training, such as someone to care for the person they care for while they attend.</p>
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5 Additional quality improvement areas suggested by stakeholders at consultation

The committee discussed the following additional areas but were comfortable that none needed to be included in the quality standard.

1. Statements from 2010 and 2013 quality standards.
2. Addressing deafness and hearing loss in adults living with dementia
 - This is covered by the diagnosis statement and the structured assessment statement.
3. Staff training in dementia care, including person-centred care
 - The committee noted that that staff training is not a standard of care in itself. The statements seek to identify the priority areas of care, and training will be one of the mechanisms to improve in these areas. Training will therefore be included in the supporting information across all statements where appropriate.
4. Promoting opportunities to engage in research at all stages of the condition
 - Research is an important part of improving care and services but is outside the scope of quality standards, which are about standards of care for each individual patient.
5. Use of person-centred, holistic care plans, developed in partnership with the person with dementia
 - NHS England are already working on making sure liaison services are in every hospital
 - The use of a care plan is covered in statement 3.
6. Dementia sub-types
 - The NICE team will consider whether there are any differences between subtypes for each statement and reference where appropriate
7. Prescribing memantine for people with moderate and severe Alzheimer's Disease
 - The committee discussed memantine at the prioritisation meeting and chose not to progress it as an area for quality improvement. Prescribing is covered in quality statement 5.

<p>8. Rehabilitation and re-enablement</p> <ul style="list-style-type: none"> • Statement 4 covers this. <p>9. Access to help with home care</p> <ul style="list-style-type: none"> • There is a quality standard on Home care for older people. <p>10. Education for communities.</p> <p>The committee suggested that the supporting information for each statement should be made more patient centred.</p>
<p>6. Resource impact and overarching outcomes</p> <p>The committee considered the resource impact of the quality standard.</p> <ul style="list-style-type: none"> • Named coordinator of care would have potential cost implications • Carer's training would have resource impact • Neutral minus overall because the quality standard will reduce risk of dementia, will reduce hospital admission and will improve health therefore reducing cost. <p>The committee suggested that the following be added to the overarching outcomes of the quality standard:</p> <ul style="list-style-type: none"> • Improved health and reduced costs • Supporting people for longer at home • Preferred place of death.
<p>7. Equality and diversity</p> <p>SW provided an outline of the equality and diversity considerations included so far and requested that the committee submit suggestions when the quality standard is sent to them for review.</p> <p>The committee agreed the following groups should be included in the equality and diversity considerations:</p> <ul style="list-style-type: none"> • Carers by association
<p>8. Any other business</p> <p>None.</p>
<p>Close of meeting</p>