**National Institute for Health and Care Excellence**

**Quality Standards Advisory Committee 2 meeting**

**Date:** Tuesday 8 December 2020

**Supporting adult carers –** review of stakeholder feedback

**Minutes:** Final

**Quoracy:** The meeting was quorate

**Attendees**

**Quality Standards Advisory Committee 2 standing members:**

Michael Rudolf (chair), Gillian Baird (vice-chair), Julie Clatworthy, Steven Hajioff, Corinne Moocarme, Jane Putsey, Mark Temple, Michael Varrow, Moyra Amess, Tessa Lewis, Jim Thomas, Peter Hoskin, Rachael Ingram, Anica Alvarez Nishio, Ian Reekie, Sunil Gupta (vice-chair), John Jolly, Nadim Fazlani

**Specialist committee members:**

Jodie Deards, Sue Jones, Anna Ferguson Montague, Clare Rachwal, Phil Taverner

**NICE staff**

Nick Baillie, Melanie Carr (MC), Julie Kennedy, Jamie Jason (notes)

**Apologies**

Allison Duggal, Lindsay Rees, Brian Hawkins, Nick Screaton, Phillip Dick

Specialist members – Debbie Hustings and Phillipa Russell

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 supporting adult carers quality standard.

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

1. **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 was the supporting adult carers quality standard specifically:

* Identifying carers
* Working with carers
* Quality of carers’ assessments
* Carers’ breaks
* Helping carers stay in work

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. The Chair asked the specialist committee members to verbally declare all interests.

1. **Minutes from the last meeting**

The committee reviewed the minutes of the last QSAC 2 meeting held on 29 September 2020 and confirmed them as an accurate record.

The Chair noted the need for an amendment to the minutes of the 11 August 2020 prioritisation meeting for supporting adult carers. The committee had agreed not to discuss the areas included in the briefing paper on ‘supporting carers at specific times’ because the issues were already covered by existing statements in other quality standards on end of life care and transition between hospital and community settings.

1. **Recap of prioritisation meeting and discussion of stakeholder feedback**

MC provided a recap of the areas for quality improvement prioritised at the first QSAC meeting for potential inclusion in the supporting adult carers draft quality standard.

MC summarised the significant themes from the stakeholder comments received on the supporting adult carers draft quality standard and referred the committee to the full set of stakeholder comments provided in the papers.

**General comments**

The committee acknowledged that there are clear differences between health and social care in relation to carers. The committee felt that there is potential for the quality standard to help to bridge the gap between health and social care.

The committee noted that there is a lot of data collected that is relevant to carers in care plans that may be helpful.

In relation to the concept of ‘circles of care’ the committee asked the team to include this in the most relevant part of the quality standard.

**Discussion and agreement of amendments required to quality**

**Draft statement 1: Carers are identified by health and social care practitioners at appointments for people with long-term conditions**

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.

Given the stakeholder feedback the committee discussed the pros and cons of changing the statement to have an organisational rather than a personal focus. The committee agreed to progress an organisational statement as it can capture some of the ways that are already being used to identify carers, including carers’ registers, GP quality markers, dementia QOF, carers’ champions, embedding carer ID into assessment processes, and hospital discharge paperwork.

The committee considered focusing the statement on health care as this may have more impact. The legal requirements to identify carers are focused on social care and not health care. However, the committee agreed to keep social care in the statement to ensure social care providers are included via commissioning processes.

The committee agreed to include ‘encouraging carers to recognise their roles and rights’ in the statement to ensure it is meaningful.

**ACTION: NICE team to amend the statement to an organisational statement covering health and social care.**

**Draft statement 2: Carers are kept up to date and contribute to decision making and care planning for the person they care for, with the person’s consent**

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.

The committee were keen to change the words ‘kept up to date’ and ‘contribute to’ as they agreed that they do not capture the intention of the statement. It was suggested that the wording should be more active and that it would be helpful to check the wording in CG138 patient experience to see if it could be helpful. It was recognised that not all carers will want to be considered an expert. The wording should reflect that carers have a choice about how they want to be involved.

There was agreement that consent does not need to be included in the statement. It can be highlighted in the supporting information instead.

The committee discussed the measures and agreed that carers can be identified and coded even if the person being cared for does not have a care plan.

**ACTION: NICE team to amend the statement wording to make it clearer that the carer has the option to be actively involved. Remove consent from wording and include in supporting information.**

**Draft statement 3: Carers having a carer’s assessment are asked about what matters most to them, including consideration of their health, wellbeing and social care needs, and work, education, or training**

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.

It was agreed that it needs to be clearer that the focus of a carer’s assessment should be on the needs of the carer rather than the person being cared for. The intention of the statement is to ask these broad questions in order to find out what is important to the carer and not trying to include everything that will be covered within a carer’s assessment.

It is important to emphasise that the carers assessment should be an ongoing flexible process and therefore reviews are included.

It was agreed that it should be made clearer that the statement applies to statutory carers assessments carried out by a local authority or delegated to the third sector.

**ACTION: NICE team to amend the statement wording to add clarity. Add detail to the supporting information to clarify that we are referring to statutory carer’s assessments.**

**Draft statement 4: Carers discuss, during their routine assessments and reviews, the value of having a break from caring and the options available to them**

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.

It was agreed that there should be clarity that this statement was not just focussing on formal carers breaks but also more broadly on the need for regular conversations where carers are reminded and asked about the need to take care of themselves.

It was also agreed that it is not helpful to focus only on routine assessments and reviews, whilst acknowledging that not all health and social care practitioners would be in a position to have these conversations with carers.

The committee discussed whether the wording of the statement should be focussed on carers, health and social care practitioners, or health and social care organisations. It was agreed that the NICE team should explore these different options.

**ACTION: NICE team to develop some different options for this statement and liaise with members outside the meeting.**

**Draft statement 5: Carers work in organisations that offer supportive working arrangements**

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.

The committee agreed the focus should be on all employers not just those in health and social care.

It was agreed that the wording could be interpreted to mean that carers should choose to work in organisations with supportive working arrangements, whereas the focus should actually be more on the employer.

The committee discussed ‘carer friendly’ accreditation, but as there is a cost associated with this it should not be included in the quality standard.

**ACTION: NICE team to review the wording to ensure clarity.**

1. **Additional quality improvement areas suggested by stakeholders at consultation**

The following areas were not progressed for inclusion in the final quality standard as the committee agreed that they were not a priority in relation to the five quality improvement areas already included:

Information, advice and signposting – this was discussed at the prioritisation meeting but not progressed

Psychological and emotional support- this was considered at the prioritisation meeting but not progressed

Carer skills training- this was discussed at the prioritisation meeting but not progressed

* Support for carers when carer role ends - this was considered at the prioritisation meeting but not progressed

Safeguarding- risk thresholds – this is beyond the scope of the NICE guideline on supporting adult carers and there are no other NICE accredited guidelines that cover this area. The committee agreed not to progress this area.

1. **Resource impact and overarching outcomes**

The committee considered the resource impact of the quality standard and agreed that it should be achievable. It was noted, however, that there could be a resource impact on employers who choose to implement supportive working arrangements.

The committee confirmed the overarching outcomes are those presented in the draft quality standard.

Time it takes for carers to recognise their caring role

Carer satisfaction with support available

Carers in employment, education or training

Carer health and wellbeing

Carer quality of life

1. **Equality and Diversity**

The committee agreed that the following groups and issues should be included in the equality and diversity considerations.

Wider cultural issues that may affect the caring role

Language – if the carer does not speak English

Migration status

Socio-economic status will limit access to employers who support carers.

It was agreed that the committee would continue to contribute suggestions as the quality standard is developed.

1. **Any other business**

None

**Close of meeting**