NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE quality standards

Equality impact assessment

Care of dying adults in the last days of life

The impact on equality has been assessed during quality standard development according to the principles of the NICE equality policy.

1. TOPIC ENGAGEMENT STAGE

1.1 Have any potential equality issues been identified during this stage of the development process? How have they been addressed?
No specific equality issues have been identified at this stage of development of the quality standard. It is noted, though, that the following potential equality issues were identified during the development of the primary source guidance: • The care of people with dementia, cognitive impairments or learning disabilities who are in the last few days or hours of life may be especially challenging, particularly in terms of recognising dying and managing pain or other symptoms. • There may be ethnic and cultural issues related to managing pain or other symptoms, and the undesirability of potential sedation in the last few days or hours of life. • People important to those dying need to be engaged in any communication or information sharing as appropriate. National policy has clarified that these should include, (where possible, with consent) those important to the dying person and as such this has implications for, for example, LGBT relationships. • People who are from traveller communities or who are homeless may have particular problems relating to accessing pharmacological management for symptom control, and anticipatory prescribing when secure storage of medication is needed. • Access to services at end life for people in prison. • Spiritual needs of those in the last few days are important to consider, including non-religion based needs. Any equality issues that may arise from these factors, or that are identified during the production process, will be considered during the development of the quality standard.

1.2 Have any population groups, treatments or settings been excluded from coverage by the quality standard at this stage in the process. Are these exclusions justified – that is, are the reasons legitimate and the exclusion proportionate?
The quality standard will cover the clinical care of adults aged 18 and over who are dying during the last 2 to 3 days of life. Exclusions are as follows: • Children and young people. The needs of children and young people in the last few days / hours of life are specific. There is a separate quality standard on End of life care for infants, children and young people in the quality standards topic library. • Palliative care before the last few days of life: The focus of this quality standard is the last few days or hours before death. This reflects the focus of the clinical guideline which targeted this period following the Neuberger review of the Liverpool Care Pathway. Care before this period, where different management may be required, is not covered in this quality standard. An existing quality standard, End of life care for adults, covers care before the last few days of life. • Service Delivery: This area is excluded from the quality standard. Service delivery was also excluded from the underpinning clinical guideline as it will be covered by a separate guideline (End of life care for adults in the last year of life: service delivery) that is in production.

Completed by lead technical analyst Paul Daly

Date 3 June 2016

Approved by NICE quality assurance lead Nick Baillie

Date 3 June 2016

2. PRE-CONSULTATION STAGE

2.1 Have any potential equality issues been identified during the development of the quality standard (including those identified during the topic engagement process)? How have they been addressed?
Prior to consultation on the draft quality standard, the potential equality issues below were identified: • People with dementia, cognitive impairments, learning disabilities or language barriers in the last few days of life may have communication difficulties. Draft statements 2 and 4 recognise that discussions about preferences for care and hydration should take account of the person's cognitive status; any speech, language or other communication needs; level of understanding; and whether they would like a person important to them to be present. • There may be ethnic and cultural issues related to managing pain or other symptoms, and the undesirability of potential sedation in the last few days or hours of life. Draft statement 2 addresses this potential issue by capturing individual preferences for care in the last days of life. Draft statement 4 also ensures that clinically assisted hydration is discussed with people who are dying, and those important to them. • People who are from traveller communities or who are homeless may have particular problems relating to anticipatory prescribing when secure storage of medication is needed. No specific measures are proposed in the quality standard to address this potential issue. It is noted that during the development of the underpinning guideline, the guideline development group's experience was that people from traveller communities, or homeless people, nearing the end of life are usually brought into a place of care where NHS staff can care for them and medication can be offered safely and securely. • Spiritual needs of those in the last few days are important to consider, including non-religion based needs. Draft statement 2 addresses this potential issue by capturing individual preferences for care in the last days of life. Potential equality issues will continue to be considered during the development of the quality standard.

2.2 Have any changes to the scope of the quality standard been made as a result of topic engagement to highlight potential equality issues?
No changes have been made to the scope of the quality standard at this stage.

2.3 Do the draft quality statements make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?
The draft quality statements do not make it more difficult for a specific group to access services compared to other groups.

2.4 Is there potential for the draft quality statements to have an adverse impact on people with disabilities because of something that is a consequence of the disability?
No.

EIA

2.5 Are there any recommendations or explanations that the committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 2.1, 2.2 or 2.3, or otherwise fulfil NICE's obligation to advance equality?
No.

Completed by lead technical analyst Paul Daly

Date 26 September 2016

Approved by NICE quality assurance lead Nick Baillie

Date 26 September 2016

EIA

Post-consultation stage

3. Final quality standard

3.1 Have any additional potential equality issues been raised during the consultation stage, and, if so, how has the committee addressed them?
No additional specific equality issues or health inequalities were identified. Although draft statements 2 and 4 have changed following consultation, they still address the potential equality issues in the way described in box 2.1 (see page 3).

3.2 If the quality statements have changed after the consultation stage, are there any that make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?
The amended quality statements will not make it more difficult for a specific group to access services. Instead, the quality statements are expected to advance equality of access by adopting an approach that is based on individualised care and support. Statement 1 will ensure that care in the last days and hours is appropriate to whether a person is nearing death, stabilising or improving. Statement 2 will identify the level of involvement a person wants in making decisions about their care. It will also identify existing, new and changed personal preferences and needs to be taken account of (including any cultural, religious, social or spiritual preferences). Statement 3 will ensure that anticipatory medicines are prescribed for people who are in settings or situations which would normally result in a delays in obtaining prescriptions to control symptoms. Statement 4 will ensure that people in the last days of life have the risks and benefits of different ways of maintaining hydration explained so that they can have their preferences taken account of.

3.3 If the quality statements have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?
No.

3.4 If the quality statements have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 3.1, 3.2 and 3.3, or otherwise fulfil NICE's obligations to advance equality?
No.

Completed by lead technical analyst Paul Daly

Date 30 January 2017

Approved by NICE quality assurance lead Nick Baillie

Date 30 January 2017

4. After Guidance Executive amendments – if applicable

4.1 Outline amendments agreed by Guidance Executive below, if applicable:
Guidance Executive approved the quality standard for publication. No amendments were sought.

Completed by lead technical analyst Paul Daly

Date 9 February 2017

Approved by NICE quality assurance lead Nick Baillie

Date 9 February 2017