National Institute for Health and Care Excellence

# End of life care (update)

**Stakeholder engagement – deadline for comments** 5pm on 27/07/20

**email**:[QStopicengagement@nice.org.uk](mailto:QStopicengagement@nice.org.uk)

Please note that this is an extension to the original topic engagement exercise which was held from 6th to 20th March 2020. If your organisation commented previously, you do not need to resubmit your comments. However, if you have additional comments that you would like to submit, you are welcome to.

Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly or arrive after the deadline.

We would like to hear your views on these questions:

1. What are the **key areas for quality improvement** that you would want to see covered by this quality standard? Please **prioritise up to 5 areas** which you consider as having the greatest potential to improve the quality of care. Please state the specific aspects of care or service delivery that should be addressed, including the actions that you feel would most improve quality.
2. End of life care services may be affected by the coronavirus pandemic. Please tell us if there are any particular issues relating to COVID-19 that we should take into account when developing this quality standard.
3. Do you have an example from practice of implementing the key development source that underpins this quality standard? If so, please provide details in the supporting information column below.

# Organisation details

|  |  |
| --- | --- |
| **Organisation name – Stakeholder or respondent**  (if you are responding as an individual rather than a registered stakeholder please leave blank) |  |
| **Disclosure**  Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry. |  |
| **Name of person completing form** |  |
| **Supporting the quality standard**  Would your organisation like to express an interest in formally supporting this quality standard? [More information.](https://www.nice.org.uk/standards-and-indicators/get-involved/support-a-quality-standard) |  |
| **Type** | **[Office use only]** |

# Quality improvement comments

|  |  |  |  |
| --- | --- | --- | --- |
| **Key area for quality improvement** | **Why is this important?** | **Why is this a key area for quality improvement?**  Evidence of information that care in the suggested key areas for quality improvement is poor or variable and requires improvement? | **Supporting information**  If available, any national data sources that collect data relating to your suggested key areas for quality improvement?  Don’t paste other tables into this table as your comments could get lost. Type directly into this table. |
| Separately list each key area for quality improvement that you would want to see covered by this quality standard.  **Example:**  Pulmonary rehabilitation for chronic obstructive pulmonary disease (COPD) | **Example:** There is good evidence that appropriate and effective pulmonary rehabilitation can drive significant improvements in the quality of life and health status of people with COPD.  Pulmonary rehabilitation is recommended within NICE guidance. Rehabilitation should be considered at all stages of disease progression when symptoms and disability are present. The threshold for referral would usually be breathlessness equivalent to MRC dyspnoea grade 3, based on the NICE guideline. | **Example:** The National Audit for COPD found that the number of areas offering pulmonary rehabilitation has increased in the last three years and although many people are offered referral, the quality of pulmonary rehabilitation and its availability is still limited in the UK.  Individual programmes differ in the precise exercises used, are of different duration, involve variable amounts of home exercise and have different referral criteria. | EXAMPLE: Please see the Royal College of Physicians national COPD audit which highlights findings of data collection for quality indicators relating to pulmonary rehabilitation. <http://www.rcplondon.ac.uk/resources/chronic-obstructive-pulmonary-disease-audit> |
| Key area for quality improvement 1 |  |  |  |
| Key area for quality improvement 2 |  |  |  |
| Key area for quality improvement 3 |  |  |  |
| Key area for quality improvement 4 |  |  |  |
| Key area for quality improvement 5 |  |  |  |
| Additional developmental areas of emergent practice |  |  |  |

# Checklist for submitting comments

* Use this form and submit it as a Word document (not a PDF).
* Complete the disclosure about links with, or funding from, the tobacco industry.
* Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
* Do not paste other tables into this table – type directly into the table.
* Underline and highlight any confidential information or other material that you do not wish to be made public.
* Do not include medical information about yourself or another person from which you or the person could be identified.
* Spell out any abbreviations you use
* Please provide concise supporting information for each key area. Provide reference to examples from the published or grey literature such as national, regional or local reports of variation in care, audits, surveys, confidential enquiries, uptake reports and evaluations such as impact of NICE guidance recommendations
* For copyright reasons, do not include attachments of **published** material such as research articles, letters or leaflets. However, if you give us the full citation, we will obtain our own copy
* Attachments of unpublished reports, local reports / documents are permissible. If you wish to provide academic in confidence material i.e. written but not yet published, or commercial in confidence i.e. internal documentation, highlight this using the highlighter function in Word.

Please return to [QStopicengagement@nice.org.uk](mailto:QStopicengagement@nice.org.uk)

NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.

Comments received from registered stakeholders and respondents during our stakeholder engagements are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.