

National Institute for Health and Care Excellence

End of life care update

Consultation on draft quality standard – deadline for comments 5pm on 09/12/20

Please email your completed form to: QSconsultations@nice.org.uk

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

We would like to hear your views on these questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?
2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place?
3. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.
4. Statement 4: Is there a specific aspect of coordination of care that this quality statement should focus on?
5. Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please provide details.

Organisation details

Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank)	Hospice UK
Disclosure	None

Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	
Name of person completing form	Esther Green
Supporting the quality standard Would your organisation like to express an interest in formally supporting this quality standard? More information.	Yes
Type	[Office use only]

Comments on the draft quality standard

Comment number	Section	Statement number	Comments Insert each comment in a new row. Do not paste other tables into this table because your comments could get lost – type directly into this table.
<i>Example 1</i>	<i>Statement 1 (measure)</i>	<i>1</i>	<i>This statement may be hard to measure because...</i>
1	Quality Statement 1 General	1	We feel this draft quality standard does broadly reflect the key areas for quality improvement in this area.
2	Quality Statement 1 Measures	1	While local systems and structures are in place to enable the collection of this data this collection and analysis does not always happen regularly and consistently across different areas.
3	Quality Statement 1 Measures	1	If a key measure is ‘evidence of local systems to systematically identify adults who are likely to be approaching the end of their life’, the proposed data sources may not accurately support this. Using the number/proportion of deceased adults who were identified on the palliative care register prior to death as a measure may not reflect the true population need as:

			<ul style="list-style-type: none"> Records of deaths can be delayed, therefore any data taken from these figures could be out of date quickly and not reflective of new changes and improvements to identification processes. There are barriers to being identified as approaching end of life, particularly for those with general frailty and coexisting conditions. Clinicians do not always feel comfortable determining and discussing when someone is approaching the end of life. <p>Suggest that this measure of how many adults are on the palliative care register is further benchmarked or compared against projections/estimates of how many adults are likely to have palliative care needs within different settings to give a more current picture of the effectiveness of identification processes.</p> <p>Suggest that attention is paid to, in particular, the diagnosis, age and ethnicity of those who were successfully identified as being at the end of life, and the diagnosis, age, ethnicity of those who died without being identified on the palliative care register. This level of analysis is crucial to understanding which, if any, population groups or conditions are missing out on care and support towards the end of life.</p>
4	Quality Statement 1 Question 3 - resourcing	1	Ensuring the timely and effective identification of adults who are likely to be approaching the end of their life is dependent on healthcare professionals across multiple different settings feeling confident in doing so. There is likely a resourcing consequence to this Quality Statement in the implementation of workforce training which covers identification and the use of local systems and tools.
5	Quality Statement 2 General	2	We are pleased to see advance care planning included in this way as a new Quality Statement.
6	Quality Statement 2 Measures	2	The focus on 'satisfaction of adults approaching the end of their life', sourced through 'local patient and carer experience surveys' could prove difficult. It is of course of the utmost importance that all those with end of life care needs receive care that is appropriate to their needs and wishes, and that every effort is made to determine patient and carer satisfaction. Surveys of carers or of patients at the end of life can however raise ethical considerations around who issues the survey and in which setting it is conducted. Currently there are not consistent local or national systems to measure patient satisfaction at the end of life, and introducing these in an extensive

			and statistically significant way would have cost implications in addition to procedural considerations.
7	Quality Statement 2 Measures	2	The draft Quality Statement suggests using the National Audit of Care at the End of Life measure for the number of people with an advance care plan on arrival at their final admission to hospital as an indicator for the success of advance care planning locally. While this is a partial measure, over-reliance on this would miss those who are not admitted to hospital in their last months of life, and particularly those with non-specialist palliative and end of life care needs. Additionally as early advance care planning discussions have been highlighted as beneficial to patients and carers, relying on a measure which only establishes that a plan is in place at the very last admission, perhaps only hours or days before death, would not encourage the early discussions and planning we know to be most effective.
8	Quality Statement 2 Question 3 – resourcing	2	It is important that health and social care practitioners across all settings are comfortable discussing advance care planning, so that individuals are able to discuss their wishes, along with their family and/or carers, at the earliest opportunity, and also so that a person’s plan can be continually updated as their wishes, circumstances, and care settings change. With this in mind specialist training on communication skills and the use of advance care planning will be necessary across but not limited to GPs, specialists, community nursing, care workers in care homes, and social workers to ensure that these discussions are effective, patient-led, and can occur in whichever setting is most appropriate to the individual.
9	Quality Statement 2 Question 4 – COVID-19	2	The COVID-19 pandemic has demonstrated the importance of advance care planning and encouraging public discussions around death and dying, these issues were acutely in focus within care home settings in particular. As the draft Quality Standard notes in its definitions, ‘advance care planning is a voluntary process of discussion’, without increased public awareness of advance care planning, and other issues surrounding death and dying, the opportunities to discuss advance care planning created by the recommendations of this Quality Standard may not be taken up by the public. It is therefore important for commissioners and service providers to consider what activities, resources and public engagement they could participate in to encourage public conversations around death and dying. There are a wealth of resources on public awareness of death and dying at Dying Matters (https://www.dyingmatters.org/overview/resources).

10	Quality Statement 3 General	3	We are pleased to see the specific inclusion of a quality statement on support for carers. The role of informal carers is key to successful end of life care for people dying at home, and this has been additionally emphasised throughout the pandemic.
11	Quality Statement 3 Measures	3	The quality measures assume a level of data that unfortunately is not currently in place. In both Numerator/Denominator examples the denominator is 'the number of carers providing end of life care to people at home' – as it stands the number of carers providing end of life care is an estimate at best, local systems do not necessarily collect this data routinely and effectively. A particular consideration is that people with caring responsibilities for someone approaching the end of life may not self-identify as being a 'carer', and therefore are likely to be unknown to the health and care system.
12	Quality Statement 3 Measures	3	Suggest that to bring this draft quality standard in line with NICE guideline NG150 supporting adult carers (specifically recommendation 1.3.1.) and the Care Act 2014, a separate measure is included to ensure that carers for people at the end of life receive a full carer's assessment. Without the comprehensive holistic needs assessments outlined in the 2011 quality standard and NG150, carers will miss out on accessing support which is appropriate to their needs, detrimentally affecting their own wellbeing in addition to the experience of the person they are caring for.
13	Quality Statement 4 General	4	This quality statement does reflect the identified key areas for quality improvement
14	Quality Statement 4 Measures	4	In: Process 'the number in the denominator whose advance care plan is shared with the practitioners involved in their care' – this line perhaps leaves too much ambiguity, should the line read 'is shared with the practitioners across all of the services and organisations involved in their care'
15	Quality Statement 4 General	4	The quality statement repeatedly states that the benefit of information sharing is that patients 'do not have to repeatedly provide information that can be shared' – while this is a benefit, the quality statement would be strengthened by also including other benefits of information sharing such as ensuring that an individual is flagged for any extra support across multiple services, and that they, and their carers, are not missed off any systems.
16	Quality Statement 4 Measures	4	It is worth reiterating that an overreliance on patient experience surveys as a measure could be problematic given their sporadic roll-out currently, and concerns about statistical significance and ethical implications.

17	Quality Statement 4 Measures	4	The use of 'preferred place' as a substitute for a successful end of life experience can raise issues, circumstances can change rapidly at the end of life, particularly for those being cared for at home, and it is not always possible to achieve care or death in a preferred place. This does not necessarily mean that a person's care was coordinated badly or that their care was below standard.
18	Quality Statement 4 Question 3 - resourcing	4	We welcome the recommendation to ensure that electronic information-sharing systems are in place across local health systems. It is important to establish where the resourcing responsibilities for this will lie, who 'leads' on the information-sharing, and at what level the decisions on which data system to use are taken. If services have to switch over to a new system to mirror those of others within their locality there will inevitably be a resourcing and training need attached to implementing that new system.
19	Quality statement 5 Measures	5	It is worth noting that 'the proportion of adults approaching the end of their life who have access to a healthcare professional' or 'an out of ours end of life care advice line' if it is interpreted as the number of people who live in an area which is technically served by an out-of-hours service, does not necessarily equate to a patient knowing about and feeling supported to use such a service.
20	Quality Statement 5 Question 4 – COVID-19	5	Hospices have been successfully providing their local areas with out-of-hours end of life care advice lines since before the pandemic. During the pandemic, hospice and end of life care services have been rapidly adapted in order to be compliant with the latest regulations. This switch to online delivery of support and services has been a positive aspect of the pandemic response and has ensured that patients and their carers have continued to have access to support during this time. It would be valuable if commissioners sought to replicate these services on a longer-term basis.

Insert more rows as needed

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.

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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.