

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)	Royal Pharmaceutical Society
Disclosure	

Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	
Name of person completing form	Iwan Hughes
Supporting the quality standard Would your organisation like to express an interest in formally supporting this quality standard? More information.	
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.
1	Adults who are likely to be approaching the end of their life are identified using locally developed systems. [2011, updated 2021]	1	<p>We are supportive of this standard and the rationale behind it. It is absolutely the case that a systematic approach that enables healthcare professionals to identify those who are likely to be approaching the end of their life should be in place in all localities.</p> <p>It should never be the case that responsibility of informing health professionals of an end of life diagnosis falls on the person or his/her family. However, at present, too often in relation to pharmacists and pharmacy teams, information about diagnosis is not systematically or routinely shared. A 2018 RPS survey of pharmacists in Wales found that only 11 per cent of pharmacists were 'always' made aware of that a person they care for is on a palliative care register. Worryingly, 63 per cent of respondents noted that they were 'never' made aware, whilst 25 per cent noted that they are 'sometimes' informed. Anecdotal evidence suggests that a similar situation also exists in England.</p> <p>Without the information being communicated to them, pharmacists depend on person actively sharing their health status or will have to see a significant change in the person's medicines regimen to become aware that the person is at a palliative or end of life stage. When information is shared with pharmacists, they can then be ready to proactively support the</p>

			<p>person and their loved ones and will be able to explore issues or worries related to both prescribed medicines and wider issues related to their diagnosis.</p> <p>It is essential that as part of the implementation of this quality statement and measures that pharmacists are notified that the person is palliative and when they are end of life.</p>
2	Adults approaching the end of their life have opportunities to discuss advance care planning. [new 2021]	2	<p>An opportunity to develop and advance care plans on the future nature of their care should always be available to those approaching the end of their life. We are therefore wholly supportive of the addition of this new quality statement.</p> <p>When an advance care plan is in place, sharing this with the pharmacy team would help to ensure that persons and their families have increased access to support from the pharmacy team and that decisions about their medicines can be discussed. The pharmacist would also be in a more informed position to assist colleagues such as nurses paramedics who may require more information to enable them to treat the person in their own home.</p> <p>Similarly, to the practice of sharing information on diagnosis discussed above, our survey of pharmacists in Wales indicated that details of advance care plans are seldom communicated to pharmacists. When asked if they had ever seen any advance care plans for their patients, 81 per cent of respondents stated that they had not.</p> <p>To maximise the benefits of advance care planning, plans should be shared with all relevant health and social care professionals, including pharmacists.</p>
3	Carers providing end of life care to people at home are supported to access local services that can provide assistance. [new 2021]	3	<p>The stresses and emotional toll of caring for a loved one undergoing palliative or end of life care cannot be underestimated. It's therefore essential that the local services and resources are in place to support families and carers at this difficult time.</p> <p>As the most accessible healthcare professional who will come in to contact with carers, pharmacists and the pharmacy teams are ideally placed to highlight sources of support for a person and their families. They can also appropriately refer to other sources of health and social care support that are open to their patients.</p>
4	Adults approaching the end of their life receive care that is coordinated between health and	4	<p>Co-ordination of care across health and social care is vitally important in ensuring that a person's death is as peaceful, symptom and stress-free as possible. This is a responsibility and should be the goal of health and social care professionals. It requires both robust systems to be in place as well as input and team working from across the multidisciplinary team.</p>

Commented [AM1]: not sure of paramedic link - but if this happens go ahead

	social care practitioners within and across different services and organisations. [2011, updated 2021]		Pharmacists should be embedded in all multidisciplinary palliative care teams to input expertise on prescribing, deprescribing and use of medicines. Pharmacists and the pharmacy team have particularly important roles following a person's diagnosis of a palliative illness to ensure that the medicines regimen is optimised, as well as to help coordinate the care and medicines supply for patients as they move from one care setting to another. Specialist palliative care pharmacist teams should also be in place in all localities and known to generalist practitioners as a source of advice on medicines issues.
5	Adults approaching the end of their life have access to support 24 hours a day, 7 days a week. [2011, updated 2021]	5	<p>A person requiring palliative or end of life care, and their families, must benefit from systems and practitioners that make sure the process of obtaining medicines, including urgent controlled medicines, is as easy and timely as possible. This will avoid any delay in treatment in all care settings and also help to ensure that a person can stay in their own homes, in comfort, without needing to be transferred to hospital for essential medicines.</p> <p>Regardless of the services set in place on local levels, it's important that both health care professionals and patients are aware of the processes that are in place to aid medicines supply in the community to avoid delays in treatment. This could be through extending existing services that are deemed to be best practice, or through improving communication regarding current systems of obtaining medicines that are in place. All prescribers issuing emergency prescriptions for end-of-life care should also take responsibility for making sure that the pharmacy they refer a person to does have stock of those prescribed medicines. At an emotional and difficult time any person and their families, sourcing important end of life medicines shouldn't be an additional worry.</p> <p>Pharmacists and pharmacy technicians must work with prescribers, nursing and care staff to ensure that the necessary medicines for a person in a timely manner. Pharmacists in the community should also make sure they communicate any services they provide that will aid medicines provision for palliative and end of life patients to local general practices. Examples of such services include just in case bags and community pharmacies that are commissioned by local health commissioning bodies to hold an extended list of essential end of life medicines.</p>

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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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.