

Haematological cancers

Consultation on draft quality standard – deadline for comments 5pm on 07/02/17 email: QSconsultations@nice.org.uk

	<p>Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly.</p> <p>We would like to hear your views on these questions:</p> <ol style="list-style-type: none">1. Does this draft quality standard accurately reflect the key areas for quality improvement? If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures? Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted.
Organisation name – stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):	Older People's Advocacy Alliance (OPAAL) UK
Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	N/A
Name of commentator person completing form:	Marie McWilliams
Supporting the quality standard - Would your organisation like to express an interest in formally supporting this quality standard? More information.	Yes

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Type		[office use only]	
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.			
Example 1	Statement 1 (measure)		This statement may be hard to measure because...
1	Equality & Diversity considerations	Quality statement 5: Central nervous system prophylaxis	<p>“Central nervous system-directed prophylactic therapy means that patients will be exposed to an increase in toxicity, resulting in an increased rate of morbidity. The increased risk of central nervous system disease in older patients specifically with the toxicity involved in repeat lumbar punctures should be considered and the patient should be involved in these difficult treatment decisions.”</p> <p>OPAAL has real concerns that there may be occasions when patients are rejected for treatment based on their age as opposed to considered based on how fit they are to withstand that treatment. Involvement in discussions about treatment decisions is the optimum opportunity for independent advocacy support for patients. An advocate will ensure that the patient is fully informed and their voice heard ahead of any decision being made.</p> <p>In many cases, information is complex and hard to remember in stressful environments with many older people not confident enough to raise questions and deferring to their doctor on decisions about treatment and care, sometimes when this is not best for them. With an independent advocate alongside them, older people can be equipped to ask the right questions of their clinician and aided to retain important information.</p> <p>It remains OPAAL’s belief that NICE Quality Standards should overtly call for the universal provision of independent peer advocacy support to ensure optimum opportunity for a positive patient experience. Whilst this does have resource implications for the NHS we see potential for major cost savings as a result of its use.</p>
2	Equality & Diversity considerations	Quality statement 6: End-of-treatment summary plan	<p>“The end-of-treatment summary plan should be clearly explained and discussed with the young person or adult (and their family members, carers or care workers, if appropriate). Information provided should be provided in a clear format and in a language suited to the person’s needs and preferences.”</p> <p>Older people affected by cancer tell us that they often struggle to understand and take in everything that they are told by health professionals. As a result, they lose confidence in themselves. An example of how this can be overcome, is explained by Tony, one of our service-users: <i>“Moving forward with the assistance of my advocate I became more confident and better enabled to meet with health professionals. I would be encouraged to write a list in relation to my physical symptoms prior to appointments. This allowed me to ensure that all my symptoms would be addressed and that I would leave my medical appointment fully mentally satisfied. My advocate would also attend them with me which gave me reassurance that I had an independent person with me. My advocate would also take notes during the appointments which we would then discuss straight after. This has helped me feel more in control and I feel better safeguarded.”</i></p>

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			<p>Diane, another service-user, notes: <i>“Andy’s (her advocate’s) continued involvement over a wide range of issues has been invaluable and he has been the most important person in my cancer survivorship experience. He supports me at meetings as well as talking through my treatments and their possible consequences.”</i></p> <p>Service-user Carol says: <i>“If Joanna (her advocate) was not with me, I don’t think I would go to these appointments. Even if I did, I would be a nervous wreck. In the appointment, Joanna takes notes so I can ask her afterwards if there is anything I have not taken in. It’s so hard to take everything in at the time if you are on your own.”</i></p> <p>It is in light of such evidence that OPAAL calls on NICE to enshrine the provision of independent advocacy support for any older person with a haematological cancer who needs it into this Quality Standard. In doing so, it will support improvement in patient management of haematological cancers.</p>
3			
4			
5			
6			

Insert extra rows as needed

Checklist for submitting comments

- Use this comment form and submit it as a Word document (not a PDF).
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Include section number of the text each comment is about eg. introduction; quality statement 1; quality statement 2 (measure).
- If commenting on a specific quality statement, please indicate the particular sub-section (for example, statement, measure or audience descriptor).
- 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
- For copyright reasons, comment forms do not include attachments such as research articles, letters or leaflets (for copyright reasons). We return comments forms that have attachments without reading them. The stakeholder may resubmit the form without attachments, but it must be received by the deadline.

You can see any guidance and quality standards that we have produced on topics related to this quality standard by checking [NICE Pathways](#).

Note: We reserve the right to summarise and edit comments received during consultations, or not to publish them at all, if we consider the comments are too long, or publication would be unlawful or otherwise inappropriate.

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Comments received from registered stakeholders and respondents during our consultations 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.