

Non-Hodgkin's lymphoma

Consultation on draft guideline – deadline for comments 5pm on 11/03/2016 **email:** NHL@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. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. 2. Would implementation of any of the draft recommendations have significant cost implications? 3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) <p>See section 3.9 of Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.</p>	
<p>Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):</p>		<p>Lymphoma Association</p>	
<p>Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.</p>		<p>The Lymphoma Association has no links with, or funding from, the tobacco industry</p>	
<p>Name of commentator person completing form:</p>		<p>Jonathan Pearce, Chief Executive</p>	
<p>Type</p>		<p>[office use only]</p>	
<p>Comment number</p>	<p>Document (full version, short version or the appendices)</p>	<p>Page number Or 'general' for</p>	<p>Line number Or 'general' for</p>
<p>Comments</p> <p>Insert each comment in a new row.</p>			

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		comments on the whole document	comments on the whole document	Do not paste other tables into this table, because your comments could get lost – type directly into this table.
Example 1	Full	16	45	We are concerned that this recommendation may imply that
Example 2	Full	16	45	Question 1: This recommendation will be a challenging change in practice because
Example 3	Full	16	45	Question 3: Our trust has had experience of implementing this approach and would be willing to submit its experiences to the NICE shared learning database. Contact.....
1	Full	42	Section 3.1.1.2	<p>Baseline FDG-PET-CT scanning is seen as standard clinical practice around the world. The recommendation not to offer FDG-PET-CT for certain subtypes and stages would put UK practice out of step with the rest of the world (following international consensus at the Lugano International Conferences on Malignant Lymphomas – see the Lugano classification and the Cheson criteria covered in <i>Recommendations for Initial Evaluation, Staging, and Response Assessment of Hodgkin and Non-Hodgkin Lymphoma: The Lugano Classification</i> (Bruce D. Cheson, Richard I. Fisher, Sally F. Barrington, Franco Cavalli, Lawrence H. Schwartz, Emanuele Zucca, and T. Andrew Lister, 2014 J Clin Oncol 32)).</p> <p>We appreciate that the evidence concerning the routine use of staging by PET scanning is very limited (either for or against), and the views expressed in the draft guideline are thus a reflection of the personal opinions of the committee. As such, it is essential that these personal views are not out of step with the views of the large majority of experts in the field and nearly all other international guidelines.</p> <p>Furthermore, not carrying out baseline PET scans could have an impact on the UK's leading role in clinical research. This is because any properly constituted trials will need to comply with the Lugano/Cheson criteria and, if baseline scanning isn't the norm, then the additional costs of such scans will have to be met from research budgets. This may mean the UK will be a less attractive place for trials, which will have a number of significant knock-on effects, including reducing access to new and innovative treatments for patients.</p> <p>Finally, clearly the above points apply to the treatment of all forms of lymphomas, but will be particularly damaging in relation to high grade or aggressive subtypes.</p>
2	Full	82 et seq	Section 4.1.4	<p>Follicular lymphoma – Bendamustine is widely used in the treatment of FL, but is not covered in the guideline. In the views of some clinicians, Bendamustine is more effective than R-CHOP or at least as good. While we appreciate that Bendamustine is currently the subject of a NICE TA (started in 2011, but which appears to have been suspended), and therefore cannot be covered in a guideline (although patients don't really understand why current TAs can't at least be acknowledged in guidelines), we are concerned that no mention of the treatment will lead to it not being available to patients in the future. Perhaps the guideline could indicate that just because certain treatments aren't included in the guideline, they shouldn't automatically be excluded from consideration. Similarly, it should also be noted that Bendamustine is now available as a generic drug, which means it is significantly cheaper than it was previously.</p>
3	Full	116	Section 4.4.2	<p>First line treatment of CD20+ DLBC Lymphoma – the recommendations in this section re not considering rituximab for patients where CHOP is contra-indicated are based on appraisal guidance (NICE TA Guidance 65) that is nearly 13</p>

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				<p>years old and does not reflect current practice and the current standard of care. In such a fast-changing area of clinical practice, patients would simply not understand or accept current treatment practice and decisions being informed by an out-of-date and inaccurate piece of guidance, which should in fact be withdrawn. We are concerned that these recommendations would reflect badly on UK clinical practice across the world, given that they do not reflect contemporary practice. In addition, the recommendations are highly discriminatory to the elderly and the less fit who may be denied the most effective treatments.</p> <p>Should TA guidance have some form of expiry date system or “Best Before” or “Use By” date, so as to avoid situations like these?</p>
4	Full	159	Section 5	<p>We’re disappointed that this section doesn’t appear to reference the high quality and accredited information and support that is available within the voluntary sector. Significant cost savings could be made if the NHS were to contract centrally with specialist lymphoma information and support organisations, rather than encouraging a multiple provision approach from individual hospitals, treatment centres and trusts.</p>
5				

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 page and line number (not section number) of the text each comment is about.
- 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 that we have produced on topics related to this guideline 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.

Comments received during our consultations are published in the interests of openness and transparency, and to promote understanding of

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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.