

Shared decision making

Consultation on draft guideline – deadline for comments 5 pm on 09/02/2021. Email: shareddecisionmaking@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 the draft recommendations presented in the guideline, and any comments you may have on the rationale and impact sections in the guideline and the evidence presented in the evidence reviews documents. We would also welcome views on the Equality Impact Assessment.</p> <p>In addition to your comments below on our guideline documents, 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 Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.</p>
Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):	The Haemophilia Society
Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	N/A

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Name of commentator person completing form:		Jefferson Courtney		
Type		[office use only]		
Comment number	Document [guideline, evidence review A, B, C etc., methods or other (please specify which)]	Page number Or 'general' for comments on whole document	Line number Or 'general' for comments on whole document	Comments
				<p>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.</p>
1	Guideline	4	16	The guidelines should more strongly suggest that at least one service user representative should be on the board (if one exists) or directly working with the responsible board member. Their role should be greater than simply a 'service user champion' and should have more direct input and responsibility.
2	Guideline	5	13	The recommendation should go further and suggest that organisations seek out disease-specific decision aids by approaching relevant patient-groups, such as The Haemophilia Society and clinician groups (e.g UKHCDO, The United Kingdom Haemophilia Doctors Organisation and the HNA, Haemophilia Nurses Association)
3	Guideline	6	9	Organisations should look to use tool and guidance created by patient-groups to aid in communication with patients and supporting shared decision-making.
4	Guideline	6	18	We would welcome a stronger recommendation that service-users should be involved in training design and delivery.
5	Guideline	8	3	Rather than suggesting linking to NICE guidance and information the guidelines should encourage linking to more accessible information such as information provided by patient organisations such as The Haemophilia Society.
6	Guideline	8	17	The guideline should recommend that appointments should be long enough to allow full consideration and discussion of the available tests and treatment options.
7	Guideline	8	27	The guideline should explicitly recommend that theoretical or potential risks are mentioned and the clinician explains what is known and to what extent the risk is quantified and understood.
8	Guideline	9	27	Relevant information should include factsheets and guidance produced by patient organisations such as The Haemophilia Society.
9	Guideline	General	General	To reach an appropriate decision in terms of treatment, it is critical to consider what outcomes matter most to the patient and that they have full and accurate information. Effective decision making requires that both NICE and NHS England provide information about available

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				<p>treatments and commissioning decisions. NICE should encourage and work with NHS England to ensure this information is published, accessible and highlighted to patients. All information, guidance and decisions should be published in plain English explaining technical terms to ensure accessibility.</p> <p>The Haemophilia Society's 2019 survey showed that many people with bleeding disorders are entirely unaware of what treatments and types of care they should be able to access. The survey also showed that only half of people with bleeding disorders felt able to influence decisions about which treatments are prescribed to them.</p> <p>Personalisation and co-decision-making should become the norm. However, this can only occur if clinicians take the time to fully understand their needs and objectives and provide them with full details of available treatments and their advantages and disadvantages.</p>
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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.
- Ensure each comment stands alone; do not cross-refer within one comment to another comment.
- **Clearly mark any confidential information or other material that you do not wish to be made public. Also, ensure you state in your email to NICE that your submission includes confidential comments.**
- **Do not name or identify any person or include medical information about yourself or another person** from which you or the person could be identified as all such data will be deleted or redacted.
- Spell out any abbreviations you use
- For copyright reasons, **do not include attachments** such as research articles, letters or leaflets. 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.
- **We do not accept comments submitted after the deadline stated for close of consultation.**

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

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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 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.

Data protection

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By submitting your data via this form you are confirming that you have read and understood this statement.

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