

## Shared decision making

Consultation on draft guideline – deadline for comments 5 pm on 09/02/2021. Email: [shareddecisionmaking@nice.org.uk](mailto:shareddecisionmaking@nice.org.uk)

	<p><b>Please read the checklist for submitting comments at the end of this form.</b> 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"><li>1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.</li><li>2. Would implementation of any of the draft recommendations have significant cost implications?</li><li>3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)</li></ol> <p>See <a href="#">Developing NICE guidance: how to get involved</a> for suggestions of general points to think about when commenting.</p>
<p><b>Organisation name – Stakeholder or respondent</b> (if you are responding as an individual rather than a registered stakeholder please leave blank):</p>	<p><b>Nuffield Council on Bioethics</b></p>

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<b>Disclosure</b> Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.		None		
<b>Name of commentator person completing form:</b>		Catherine Joynson, Assistant Director		
<b>Type</b>		[office use only]		
<b>Comment number</b>	<b>Document</b> [guideline, evidence review A, B, C etc., methods or other (please specify which)]	<b>Page number</b> Or <b>'general'</b> for comments on whole document	<b>Line number</b> Or <b>'general'</b> for comments on whole document	<b>Comments</b>  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	Guideline	General	General	<p>We welcome this guideline as a positive contribution to the creation of healthcare environments that foster good, collaborative relationships between patients and healthcare staff.</p> <p>In 2019, the Nuffield Council on Bioethics published a briefing note on the disagreements that can arise between parents and healthcare staff in the care of critically ill children (see <a href="https://www.nuffieldbioethics.org/publications/disagreements-in-the-care-of-critically-ill-children">https://www.nuffieldbioethics.org/publications/disagreements-in-the-care-of-critically-ill-children</a>). We suggested ways to prevent protracted and damaging disagreements developing, or to resolve them more quickly. The aim should be:</p> <ol style="list-style-type: none"> <li>1 Good communication between families and healthcare staff and an understanding of differing perspectives;</li> <li>2 Appropriate involvement of parents in discussions and decisions about the care and treatment of their child;</li> <li>3 Timely use of effective resolution interventions in cases of disagreement; and</li> <li>4 Attention to the profound psychological effects that disagreements can have on families and healthcare staff.</li> </ol>

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			<p>Taken together, the recommendations of the guideline helpfully promote collaboration, communication and informed patient choice in healthcare settings. Specifically, many of the recommendations align with the areas for action we set out in our document that relate to the first two aims above. For example:</p> <ul style="list-style-type: none"> <li>• “1.1.5 Develop an organisation-wide plan to put shared decision making into practice” – we suggested those responsible for national policy making in relation to healthcare practice (such as NICE) should support NHS trusts across the UK to develop processes for recognising and managing disagreements between parents and healthcare staff, such as introducing conflict management frameworks.</li> <li>• “1.1.6 Organisations should ensure that knowledge, skills and confidence to support shared decision making are included in the training and continuing professional development of all healthcare staff” – we suggested making ethics, communication, and conflict management training for paediatric healthcare staff more widely available, or even compulsory.</li> <li>• “1.2 Putting shared decision making into practice” – we suggested exploring ways in which those parents who want to can be more involved in discussions and decisions about their critically ill child.</li> <li>• “1.2.5 ...offer to arrange additional support for them if they do not have, or do not want, support from a partner, friend or carer. Support could come from a nurse, social worker, translator or volunteer (for example, an advocate)” – we suggested making independent advocates and financial support, such as legal aid, available to parents who are in legal disputes with hospitals.</li> </ul> <p>We would like to suggest that NICE considers including information in the guideline on shared decision making specifically between parents of sick children and healthcare staff, given that this can differ from decisions about adult patients.</p> <p>Before any kind of medical intervention can be given to a baby or young child, the consent of the parents or guardians must be sought by the healthcare team (except in emergency situations where immediate steps need to be taken). This also applies to decisions to withdraw or withhold life-sustaining treatment. Parents can request a particular course of action, but there is no obligation on healthcare staff to provide treatment that they do not believe to be in the best interests of the child. In practice, this means healthcare staff and parents of young children and babies ideally should both agree to the care and treatment that is to be provided through a process of shared decision making.</p> <p>However, if disagreements arise that cannot be resolved, hospitals must apply to the appropriate court for an independent ruling before proceeding with a course of action that the parents do not consent to. Recent high-profile court cases in the UK have highlighted the damaging effects that these kinds of disagreements can have</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.**

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- **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](#).

**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.

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