

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):	Association for Improvements in the Maternity Services (AIMS)
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:		Jo Dagustun		
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 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	From a reader's perspective, the ordering of this document content is confusing. Please consider changing the order. For example, the document begins by discussing how shared decision making can be embedded at an organisational level before introducing what shared decision making is/ should look like in practice.
2	Guideline	General	General	AIMS strongly believes that a more appropriate term for 'shared decision making' would be 'supported decision making', and would note that this new terminology is increasingly being adopted in the context of maternity services, and as such is supported by NHS-England and Improvement. We see no reason why this shift in terminology should not occur more widely, and not to make such a wider shift would be unhelpful. Whilst we understand that 'shared' refers to the sharing of information between healthcare professionals and service users as part of the decision making process - rather than to the decision, and the person with the authority to make the decision itself - we feel that the terminology scattered around this guidance (and in the supporting documentation) - raises an important lack of clarity around whose right it is to make the final decision. This lack of clarity is evident throughout the documents. In our view, the phrase 'shared decision making' does not appropriately convey the legal rights of bodily autonomy that exist in the UK and the fact that decisions are always for the service user to make (except in rare situations where an adult lacks capacity.) We recognise that some people will not always want to make a decision about their healthcare options, and would rather leave this to the healthcare professional: even in these cases, however, we feel that the term 'supported decision making' is the better term.
3	Guideline	General	General	We feel, as this is a document which will be read and used by a variety of stakeholders (including service users), that the tone throughout does not adequately convey the collaborative nature of 'shared decision making'. It reads more like something which is being done to a person and that they are being 'allowed' to participate. There is little recognition that HCPs have an obligation to provide service users with the information they require to make a decision

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				and then to support them in the decision that they make. There is no consideration given to the fact that service users may initiate a conversation about their choices, and that they are active and equal participants in the information sharing process - and indeed the primary stakeholder - with the ultimate decision about their care being for them to make.
4	Guideline	5	4-6	Who decides what good practice in shared decision making looks like? Please consider making recommendations for gathering service user feedback about whether shared decision making was managed well, and also how best to gather service user feedback.
5	Guideline	6	26	Whilst supporting the overall aim here to promote service-user decision-making, AIMS believes that it is important that the term shared decision making - if this is retained - is not used in any service-user facing context, as this is likely to be highly misleading and confuse the issue of who has the right to make a decision.
6	Guideline	7	1	Rewrite this bullet point to reflect the fact that the service user is always, excepting certain circumstances, the decision maker.
7	Guideline	7	3-5	We are unsure what 'interventions' means in this context: please clarify. We suggest that this point in the guidance might be a sensible place to flag up the contribution that improved staff continuity (or continuity of carer) can make to improved decision-making on the part of the service-user. Indeed we would suggest that staff continuity is crucial to improving how the service supports decision-making, and should be clearly recognised as such in this guidance. If this issue cannot be included due to lack of sufficient evidence, please consider this as a research recommendation.
8	Guideline	8	2	We are unsure how helpful the wording 'what they hope to gain' is in this section.
9	Guideline	8	18	Care should be taken around wording to ensure that service users understand that this is their right rather than something they are being "allowed" to be involved in. We would suggest: "Ensure the person understands they have the right to make choices about their treatment or care, and that it is their choice how much they wish to be involved in any discussion."
10	Guideline	8	25	The practitioner should be seeking the opinion of the person whose care it is to find out how each option aligns with the person's aims rather than explaining how it aligns with their aims to them.
11	Guideline	8	27-29	We feel that it is important in this part of the document to give consideration to the risks that people may have identified, given their unique knowledge and understanding of their individual situation. We would like to see some words added here that make it clear that the practitioner should ensure that the person's views on risks should be seen as a valid consideration. Otherwise, this currently reads as the imparting of information from the practitioner to the person, rather than a two way sharing of information and opinion.
12	Guideline	9	2	We feel that the wording here suggests that it is only the service user who may have misconceptions.
13	Guideline	9	3	AIMS feels strongly that providing for a sufficient amount of time for appointments is an important part of the supported decision making process. This may require some organisational re-planning to ensure that resources are in place to support this (for example, as called for in the National Maternity Report (Better Births, 2016, 6.11)).
14	Guideline	9	6	We feel that the use of the word 'checking' in this section does not give appropriate recognition to the fact that both sides are experts: it feels aggressive and power laden. Is there an opportunity for service users to check that the practitioner also understands the information in relation to their specific circumstances and what is important to them

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15	Guideline	9	11-13	AIMS fully supports this point although we do not feel as though this is always reflected throughout the document. We would welcome the clear inclusion of the point that a difference of opinion should be noted, whilst making it clear that it is the service user who makes the decision.
16	Guideline	9	14	We are unsure why it is a joint decision and what happens if the service user and practitioner do not agree. Can this be clarified to the effect that the service user is the final decision-maker?
17	Guideline	9	16	We feel that this section could be worded better to show that it is about clarifying understanding on both sides.
18	Guideline	9	20	As mentioned above, differences of opinions could also be recorded if the practitioner felt it was necessary.
19	Guideline	10	1-6	We note that the guidance referred to here has not been adopted across all services. To ensure patient equity, we do not understand the inclusion of the word 'consider' in this context: why would this not be a universal offer? We would also note - thinking of midwives - that GPs are not the only relevant healthcare professional in this context.
20	Guideline	10	6, 7	We feel that the language here is misleading and does not fit with our understanding of the law. Replace 'share in making' with 'make decisions'.
21	Guideline	11	7-14	To conserve scarce healthcare resources, AIMS suggests that it would be preferable to recommend the production of such decision aids at the national level, with further clarity around who should have the role of producing them (and who should be involved in their production). If they were to be produced at national level, it would then also be more straightforward to properly consult on their content; this is key to ensuring their trustworthiness and widespread support amongst health care professionals and service users alike. Where organisations/ systems have adopted decision aids to use locally, we suggest that these should <u>always</u> be easily accessible via the provider website, as well as in other formats to meet individual needs.
22	Guideline	11	16	AIMS supports this section on communicating risks, benefits and consequences.
23	Guideline	12	5-7	We are pleased to see recognition given to the fact that information around risks, benefits and consequences should be personalised but would like to see some reference made to the fact that healthcare professionals may need to go away to find information out, and present alternatives. We feel that this will ensure that people are being provided with information that is truly personalised to their situation.
24	Guideline	14	3	AIMS is concerned about the use of the term 'joint decision' in the definition of 'shared decision making'. This does not give appropriate weight to the fact that the choice is always, excepting certain circumstances, for the service user to make.

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.

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- 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](#).

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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