

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>
<p>Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):</p>	<p>The Royal College of Physicians and Surgeons of Glasgow</p>

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Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.		none		
Name of commentator person completing form:		Dr Richard Hull FRCP Glas, Honorary Secretary with the assistance of expert reviewers (medical professional and lay)		
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.
Example 1	Guideline	16	45	We are concerned that this recommendation may imply that
Example 2	Guideline	17	23	Question 1: This recommendation will be a challenging change in practice because
Example 3	Guideline	23	5	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.....
Example 4	Guideline	37	16	This rationale states that...
Example 5	Evidence review C	57	32	There is evidence that ...
Example 6	Methods	34	10	The inclusion criteria ...

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Example 7	Algorithm	General	General	The algorithm seems to imply that ...
1	Guideline	General	General	<p>The Royal College of Physicians and Surgeons of Glasgow although based in Glasgow represents Fellows and Members throughout the United Kingdom. While this report is related to England, many of the recommendations are applicable to all devolved nations including Scotland. They should be considered by the relevant Ministers of the devolved governments.</p> <p>The College welcomes this Guidance although it considers it aspirational and giving an ideal. This may not be entirely practical given the considerable constraints within the NHS (exacerbated by the COVID-19 crisis). There appears to be no evaluation of the full financial consequences of this guideline.</p> <p>The College notes the committee comprised of lay people (4-5), palliative care consultants (2), GP (2), mental health professional (2), psychologist (1), orthopaedic trainee (1), pharmacist (1), primary care palliative care advisor (1), primary dental care professional (1), ethicist (1), academic in epidemiology and public health (1) (three others listed have academic posts).</p> <p>While it is impossible to have every speciality recognised on the committee, there appears no representative from specialities which have a long-term practice of shared decision making such as surgery, oncology, respiratory medicine, elderly health, rheumatology, rehabilitation or pain management (other than palliative care). While there were five lay members of the committee, for such an important issue wider consultation may be necessary. It perhaps would have been helpful to consider focus groups for professionals and the public in the methodology.</p>
2	Guideline	General	General	<p>A lay reviewer felt “it is ironic that the ends and means (ie the purpose) of this document, despite careful reading, are not readily apparent. It is, of course, a consultation document. But to what end? NICE is obviously part of the way through its project (https://www.nice.org.uk/guidance/indevelopment/gid-ng10120/documents), which has been operational since mid-2019 and which it expects to conclude in June this year. Is this document aspirational or a consultation on likely proposals (or a mixture)?”</p>

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				<p>The structure of the document is unhelpful to this reader; while the table of contents on page 3 does give some clues about what is to come, a summary of where this consultation has got to, where it is, and where it is going would be most useful. Some of the links are weblinks and some indicate that a defined term is being used.</p> <p>There are references to documents which contains research that is unintelligible to this layperson. The research may be highly pertinent. How is the layperson to know? Diagrams, tables, illustrations, and explanations (rather than a link) would be useful. Without being able to understand what has been researched, the reviewer did not know the answer to such basic questions as:</p> <ol style="list-style-type: none"> 1. Assuming that shared decision-making is capable of <i>quantification</i>, what metrics are being used? 2. Is shared decision-making partly (or wholly?) <i>qualitative</i>? What means should be used to investigate that aspect of decision-making? 3. Might parallel longitudinal studies of patients and doctors be useful?
3	Guideline	1	5	Another noted the section on “Who is it for?” does not mention people under the age of 18 specifically. It is unclear whether the guidelines do not apply to minors and their parents/carers or whether it is this just not mentioned? As this is read by lay people there needs clarity.
4	Guideline	4	17	It is unclear what is being meant by “people who use services as organisation-wide ‘service user champions’ for shared decision making”.
5	Guideline	6	8	The “three talk” model is not widely known in clinical medicine. Our reviewer did a limited search on the internet possible suggesting that the model is controversial and/or in flux (https://www.bmj.com/content/359/bmj.i4891). As George Box said, all models are wrong, some are useful. It would be helpful to know how it has been used in practice. What is it about the model which practitioners and patients need to know and, by using it, do differently?

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6	Guideline	8	5	<p>This paragraph lacks mention of those who are unable to read or write. Illiteracy is commoner in those particularly from a BAME background whose first language is not English.</p> <p>When identifying what additional support is required for those with sensory impairments it would be useful if such support was actually available. The reviewer attempted to get hospital appointment letters in large print for an elderly lady with macular degeneration. While this is a national requirement and has been a local standard for at least the last ten years, no such facilities exist because the centralised computer system is incapable of providing such facilities.</p>
7	Guideline	9	10	<p>The suggested process for carrying out discussions during appointments is fine. It contains all the elements expected except that “conflict resolution” is not mentioned anywhere. There just seems to be an expectation that discussions will go as planned and a mutually acceptable course of treatment will be agreed. What happens when the patient/carers/advocate completely rejects to options presented and proposes a course of action that is either not acceptable or available to the medical professional. This needs to be discussed.</p> <p>The reviewer also pointed to the issues raised in https://casereports.bmj.com/content/bmjcr/14/1/e237942.full.pdf where a seriously ill patient had different priorities to his medical team.</p>
8	Guideline	9	24	<p>All output information and letters should be in a format that can be easily read and understood. Although NICE documents are quoted as an example, many are in a form which cannot be understood by the lay public.</p> <p>Consideration needs to be given to lay versions of NICE documents and compliance with readability standards such as the “crystal clear standard” of the Plain English Campaign.</p>
9	Guideline	General	General	<p>Our lay reviewer concluded “in summary, there are some useful observations in the document about organisational, cultural, and individual approaches to shared decision making. Top-down</p>

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				initiatives may not work, particularly when the culture is not receptive to a strategic initiative. This Guideline needs to define what are the most effective tasks that patients and practitioners might adopt to make measurable (quantitatively/qualitatively) improvements in shared decision making with efficient use of time”.
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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](#).

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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