

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Improving how patients and the public can help develop NICE guidance and standards

Consultation question	Response to consultation question
	Please do not paste other tables into this table, because your comments could get lost. Please type directly into this table.
1. What are your views on our stated principles for involving lay people in developing our guidance and standards? (Page 7)	<p>1. The intent is good, but the claim that the proposed principles are evidence-based is both superfluous and factually incorrect. The acceptance of anecdote in the review and decision process (which we welcome) is specifically excluded from a purely evidence-based approach.</p> <p>2. Under what circumstances might it be inappropriate to involve lay people in the choice of topics? The footnote to bullet 1 of para 18 seems to contradict the basic principle outlined in para 49 where it says that NICE “will create an organisational culture that puts lay people at the heart of NICE's work”.</p> <p>3. If you are going to involve patients with an active cancer (e.g. advanced prostate cancer) and undergoing active treatment, it should be recognised that it is often difficult to commit to meetings on future dates. These are the very people who should be encouraged to become involved.</p> <p>4. We welcome the proposal to provide feed-back to participants, which is currently lacking, but the confidentiality constraints must not be so rigorous that they prevent participants sharing this feed-back with the organisations they represent.</p>
2. What are your views on our plans to standardise the approaches to how we engage with and involve lay people across our guidance and standards programmes? (Page 8)	<p>5. We welcome the proposal to standardise.</p> <p>6. We are concerned that the arrangement of a pool of lay members will not allow for an open and honest debate which may include challenging and perhaps sometimes controversial views from patient members.</p>
3. What are your views on our proposal to involve lay people earlier and keep them involved throughout the development process? (Page 9)	7. We welcome this.

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4. What are your views on our plans in relation to how we find and take account of information about people's experiences of care? (Page 9)	8. We welcome this, whilst recognising that such testimony is, by definition, anecdotal, and therefore cannot fit with the claim of an evidence-based approach. 9. Furthermore, it should be recognised that many of the people you need for the best information are patients with cancers and receiving active treatment, preferably on the drug being appraised. These patients are often struggling with the side affects of the treatment which can make attending some meetings difficult.
5. What are your views on our proposed new approaches to recruiting lay people to our decision-making bodies? (Page 10)	10. This section gives us the most concern. We fear that the statement "To ensure we take account of a range of views, the pool would need to be refreshed on a regular basis" might imply that those lay members who speak out and offer challenges are the ones you look to "refresh". This would be the very opposite of the ostensible aim of the proposals, namely to "improve participation, engagement and involvement of lay people at NICE", (see para 17 of the paper). 11. We do not understand how lay people can be expected to have a broad knowledge of different treatments.
6. What are your views on our proposal to introduce a formal feedback process for the lay people working with us? (Page 11)	12. We welcome this, but it should not be constrained by confidentiality considerations.
7. What are your views on our proposal to make better use of social media, alongside our existing communication channels? (Page 11)	13. Used with care this could be good, but it must be remembered that, on social media, people mostly only get to see what they agree with.
8. What are your views on increasing NICE staff awareness and knowledge of public involvement? (Page 12)	14. This aspect, which we support in principle, appears to be contradicted by footnote 2 (page 7), which implies that involvement of lay people in NICE affairs will only happen "If these opportunities exist ...". Surely, if the principle is to make "involving lay people everyone's business", by definition those opportunities will exist. 15. We would like it on record that we have always found Public Involvement Programme to be extremely helpful and understanding of patients needs, especially when patients are involved with NICE for the first time.

General comments on the consultation paper		
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General		<p>16. Our comments are based on the following shortcomings that we have experienced in being involved with NICE in developing guidance and standards:</p> <ul style="list-style-type: none"> <li>• There is a lack of transparency about how much influence patient input has on the final decisions.</li> <li>• Treatment of lay experts by the Chairs of NICE committees has on occasion been discourteous and unsympathetic; patients' views are sometimes not given the weight they deserve. There is often little or no opportunity for a patient to get his or her point across. Patients have to be proactive to become involved in the discussion and the environment needs to be conducive to effective dialogue.</li> <li>• Data derived only from clinical practice is ignored. (examples are Degarelix, Cabazitaxel)</li> <li>• At scoping meetings there is a feeling that outcomes are already cut and dried. For example at one meeting on Enzalutamide in Manchester, the meeting took half an hour and patient representatives were never offered an opportunity to comment.</li> <li>• Rules governing confidentiality are not enforced consistently or fairly; the release date of information can be open to interpretation. This has important PR implications for a small charity such as ourselves. For example there was an incident recently where we were criticised after having followed the rules, when we had not been informed of an informal agreement between NICE and other members of the panel by which a co-ordinated release was agreed.</li> </ul> <p>17. It is our belief hope that the new proposals will go some way to correcting these shortcomings.</p>
General	<a href="#">Click here to enter text.</a>	18. Whilst we applaud the aims of the paper and the consultation proposals, we observe (with a degree of sympathy) that NICE is probably attempting to achieve the impossible, having placed itself "between a rock and a hard place" of its own

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		<p>making. (This is nicely summarised in para 8 of Appendix A.) NICE likes to be seen as an “evidence-based organisation”. To be true to that claim, anecdote can have little role to play in the discussion. Patients’ input to the NICE processes, however, are almost exclusively built on their own or their friends’ experiences - anecdote, by definition. We’re not sure there’s any satisfactory way to square that circle. There is little in the document to see how this can be achieved.</p> <p>19. We fear that the way NICE will choose to implement these proposals will not pay due regard to effective patient involvement, and end up not taking the opportunity to develop a real partnership with patients. . Without an adequate explanation of how NICE intends to address real patient involvement as stakeholders in the process, and the document provides none, there is the very strong risk that the general public will continue to suspect that NICE decisions are driven more by financial and political considerations than they are by concerns for patient well-being.</p>
General	<a href="#">Click here to enter text.</a>	<p>20. We have significant reservations about the proposed approach to lay person recruitment. At the moment, NICE has a supply of patient experts, all of whom have in-depth knowledge of managing and living with their disease. Many will have some experience of a drug or technology being appraised. This is vital to the fair appraisal of the given treatment, and is knowledge which might be lost if lay members were recruited from an existing pool.</p>
21		<p>21. It is not clear to us how standardisation will “ensure the right input from the right people at the right time”; if anything, rigid standardisation will have the opposite effect. Flexibility, within a broadly standardised framework is what is required.</p>
30		<p>22. “Manufacturers to submit evidence on patients’ experiences”: such evidence will not, by definition, be disinterested. No information is given about how</p>

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		committees will balance such evidence against the (equally partial) views of lay persons.
35	36,37,38,39,40,41	<p>23. We do not support recruiting committee members from a pool of lay members. Not only will there be a huge loss of knowledge from patient experts nominated from patient organisations, but the whole process is open to manipulation which will result in an unbalanced committee, engineered to produce results amenable to NICE's political masters. Something similar actually happened with the Degarelix Appraisal which went to appeal. To say that committees would be continuously refreshed seems to suggest that members whose views do not coincide with the Appraisal Committee's might find themselves being replaced.</p> <p>24. Patient experts should still be recruited primarily from disease specific patient organisations. These are the patients with the condition and have the best knowledge on what it is like to live with it and the consequences of new treatments. A pool of lay members would not have the same expertise. The suggestion that patients would only be recruited "if there is no suitable patient expert in the pool" goes directly against the stated aims of the proposals to "improve participation, engagement and involvement of lay people at NICE", (see para 17 of the paper).</p>