

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

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

Comments form

Name:	Cancer52
Role: (Please select from list)	Medical or dental professional <input type="checkbox"/> Nursing or midwifery professional <input type="checkbox"/> Allied health professional <input type="checkbox"/> Scientific or technical professional <input type="checkbox"/> Pharmacist <input type="checkbox"/> Healthcare support services <input type="checkbox"/> Public health professional <input type="checkbox"/> Social care professional <input type="checkbox"/> Care support services professional <input type="checkbox"/> Manager <input type="checkbox"/> Research or academic professional <input type="checkbox"/> Admin or clerical professional <input type="checkbox"/> Student <input type="checkbox"/> Patient / service user <input type="checkbox"/> Carer <input type="checkbox"/> Other <input type="checkbox"/> Please specify alliance of more than 90 charities working in rare and less common cancer field

<p>Organisation type: (Please select from list)</p>	<p>Primary care <input type="checkbox"/></p> <p>Community care <input type="checkbox"/></p> <p>Secondary care <input type="checkbox"/></p> <p>Tertiary care <input type="checkbox"/></p> <p>Long term residential care <input type="checkbox"/></p> <p>Local authority / Healthwatch Local <input type="checkbox"/></p> <p>Clinical Commissioning Group <input type="checkbox"/></p> <p>Commissioning Support Unit <input type="checkbox"/></p> <p>NHS England <input type="checkbox"/></p> <p>Public Health England <input type="checkbox"/></p> <p>National regulator / advisory body / arm's length organisation (non departmental government body) <input type="checkbox"/></p> <p>University / college / school <input type="checkbox"/></p> <p>Pharmaceutical / medical technologies <input type="checkbox"/></p> <p>Advocacy and patient / service user support group <input checked="" type="checkbox"/></p> <p>Other <input type="checkbox"/> Please specify Click here to enter text.</p>
<p>Email address:</p>	<p>info@cancer52.org.uk</p>
<p>Have you or your organisation received any payments, grants or other funding from the pharmaceutical industry in the past three years?</p>	<p>yes</p>

Consultation question	Response to consultation question
1. What are your views on our stated principles for involving lay people* in developing our guidance and standards? (Page 7)	Please see our statement , attached, called 'what's the point'
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>Please see our statement , attached, called 'what's the point' BUT to summarise - agree with the principles given below - though more substance will be required.</p> <p>Involve people early</p> <p>Incorporate information on people's experiences of cares and services</p> <p>Take new approaches to recruitment</p> <p>Feed back to participants</p> <p>Use social media</p> <p>Make involving lay people everyone's business (by which we assume 'everyone' means everyone within NICE and the NICE systems)</p> <p>Difficult to comment on 'standardise approaches' - too wide a topic</p> <p>Overall - devil is in the detail here though and there is no mention of measuring impact; or of how NICE will work with patient groups to ensure that they are involved appropriately at the right times, and not have their time wasted or their patients stressed unnecessarily and to no end</p>

* For the purposes of this consultation paper, the term 'lay people' is used to describe the patients, carers, people who use services, experts by experience, survivors and members of the public who contribute to the development of NICE guidance and quality standards. This includes people with a care or support need, condition or disability; family and friends who provide unpaid care; people who work at voluntary and community sector organisations; and people who have an advocacy role.

3. What are your views on our proposal to involve lay people earlier and keep them involved throughout the development process? (Page 9)

We agree with this principle.

In support of this statement - we have asked for

reinstatement of scoping workshops and patient involvement therein ... as the workshops seem to have disappeared. They are important as they set the tone, scope and context for the whole process and mean that patients do not come into the process early enough

early involvement of patients in the process

a conversation on a particular appraisal between NICE and patient groups pre the scoping workshop that helps identify where all parties think key points for patient involvement in the decision making process on this particular decision will be. Aim of this discussion is to prevent patient group time being wasted and to help focus effort where it will have most impact

acknowledgement that the [PACE meetings](#)ⁱ held by SMC are regarded by patient groups as best practice, ahead of the curve etc

NICE is now the only HTA body in the UK that doesn't hold patient focused meetings like PACE (a particular issue for rare and less common cancers, as PACE is only held for orphan drugs and End of Life) – could this be a review panel that is held throughout the process?

There should be greater flexibility on when patients can be involved. An example was cited where towards the end of an appraisal, it became apparent that because of the direction of travel, a particular patient case study would be valuable to illustrate a particular point. However, as that patient had not been registered at the beginning of the process, they were not permitted to be involved. As it is not always possible at the outset to know which individual patients could best support an appraisal, greater flexibility should be permitted.

<p>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)</p>	<p>Believe that NICE needs to be clearer (and this may be the plan) about what will be accepted ...</p> <p>Views from patients and carers?</p> <p>Views garnered from social media, online forums, survey monkeys, group discussions ?</p> <p>Use of technology - webinars, teleconference calls, etc - ie do we need to actually move people who are not well around the country in order to get their voice hear?</p>
<p>5. What are your views on our proposed new approaches to recruiting lay people to our decision-making bodies? (Page 10)</p>	<p>Believe that while recognising good intentions of this set of proposals it looks overly complex and is focusing at the wrong end of the spectrum. 'Specialist lay people' sounds like an oxymoron. Better to focus on individual patients or carers who actually are affected by whatever drug/condition under discussion rather than trying to brief people who know little to become 'experts' on what sounds like too wide a range of topics.</p>
<p>6. What are your views on our proposal to introduce a formal feedback process for the lay people working with us? (Page 11)</p>	<p>Fine, as far as it goes.</p> <p>We have asked for</p> <p>a feedback process that demonstrates that the voice of the patient has been heard, on a point by point basis, and responded to in a constructive and meaningful way. The response doesn't of course need to an agreement with every point raised, but one that shows it's been considered. NICE used to do this for comments made during the scoping process. However, comments were usually 'Comments noted. No action required'</p> <p>clarity is required for patient groups so they can understand their impact on an appraisal. Currently, there is no way of telling whether our views have been taken into account or not, or if we've successfully had any influence on a final appraisal decision.</p> <p>clarity on where patient groups can most add value in an appraisal – where are the areas of uncertainty, where are the gaps in the evidence base? If there was more transparency about this, patient groups could focus on the key areas of an appraisal rather than spending significant time on making points that the committee already agreed with.</p>

	<p>a process that allows the patient voice to actually have a measurable impact. Ideally this would be a vote - as it is noticeable that patients are the only ones who aren't allowed one.</p> <p>If there's no vote ... then alternatively/additionally make patient views part of a comprehensive scoring process (of which the QALY is only one part)</p>
<p>7. What are your views on our proposal to make better use of social media, alongside our existing communication channels? (Page 11)</p>	<p>Again all good in principle, though no mention of how much resource would be put against this workstream. Social media is very easy to set up but very difficult to maintain at a meaningful level.</p>
<p>8. What are your views on increasing NICE staff awareness and knowledge of public involvement? (Page 12)</p>	<p>Good in principle though nothing that suggests that this will be a 'top down' culture shift.</p> <p>We have asked for</p> <p>A shift in culture at NICE which means that from the top down the patient voice is recognised as a key driver in decision making, not one that comes in late in the day and is accommodated but not commented on or measured and coming from the bottom up</p> <p>a shift in tone from one that appears to refer to everyone, apart from the person who has a rare or less common cancer, as 'professional'</p>

General comments on the consultation paper		
<p>Number of the section your comment primarily relates to (please enter only one)</p> <p>Indicate '<u>general</u>' if your comment relates to the whole document</p>	<p>Other section numbers your comment relates to</p>	<p>Please insert each new comment in a new row</p>

<p>general</p>	<p>Click here to enter text.</p>	<p>clarity, impact and feedback clarity is required for patient groups so they can understand their impact on an appraisal. Currently, there is no way of telling whether our views have been taken into account or not, or if we've successfully had any influence on a final appraisal decision.</p> <p>clarity on where patient groups can most add value in an appraisal – where are the areas of uncertainty, where are the gaps in the evidence base? If there was more transparency about this, patient groups could focus on the key areas of an appraisal rather than spending significant time on making points that the committee already agreed with.</p> <p>a process that allows the patient voice to actually have a measurable impact. Ideally this would be a vote - as it is noticeable that patients are the only ones who aren't allowed one.</p> <p>If there's no vote ... then alternatively/additionally make patient views part of a comprehensive scoring process (of which the QALY is only one part)</p> <p>a feedback process that demonstrates that the voice of the patient has been heard, on a point by point basis, and responded to in a constructive and meaningful way. The response doesn't of course need to an agreement with every point raised, but one that shows it's been considered. NICE used to do this for comments made during the scoping process. However, comments were usually 'Comments noted. No action required'</p>
<p>General</p>	<p>Click here to enter text.</p>	<p>flexibility and culture</p> <p>a flexibility in process that allows the patient and other stakeholder input at the committee meeting stage to be placed early on the agenda and not necessitate patient presence throughout the initial health economics presentation</p> <p>a flexibility in technology that allows patients not to have to travel - from hospital? to the meeting. Teleconference, webinar, etc</p> <p>a shift in tone from one that appears to refer to everyone, apart from the person who has a rare or less common cancer, as 'professional'</p> <p>shift in culture at NICE which means that from the top down the patient voice is recognised as a key driver in decision making, not one that comes in late in the day</p>

		and is accommodated but not commented on or measured and coming from the bottom up
General	Click here to enter text.	<p>process changes</p> <p>reinstatement of scoping workshops and patient involvement therein ... as the workshops seem to have disappeared. They are important as they set the tone, scope and context for the whole process and mean that patients do not come into the process early enough</p> <p>early involvement of patients in the process</p> <p>a conversation on a particular appraisal between NICE and patient groups pre the scoping workshop that helps identify where all parties think key points for patient involvement in the decision making process on this particular decision will be. Aim of this discussion is to prevent patient group time being wasted and to help focus effort where it will have most impact</p> <p>acknowledgement that the PACE meetingsⁱⁱ held by SMC are regarded by patient groups as best practice, ahead of the curve etc</p> <p>NICE is now the only HTA body in the UK that doesn't hold patient focused meetings like PACE (a particular issue for rare and less common cancers, as PACE is only held for orphan drugs and End of Life) – could this be a review panel that is held throughout the process?</p> <p>There should be greater flexibility on when patients can be involved. An example was cited where towards the end of an appraisal, it became apparent that because of the direction of travel, a particular patient case study would be valuable to illustrate a particular point. However, as that patient had not been registered at the beginning of the process, they were not permitted to be involved. As it is not always possible at the outset to know which individual patients could best support an appraisal, greater flexibility should be permitted.</p> <p>We need to find a way of capturing quality of life issues, the impact of a new drug that really changes the lives of patients and carers. There was a previous attempt to do this through Value Based Pricing – this died a death not because Quality of Life was deemed unimportant, but because it was difficult to find a way of capturing it. If quantifying it remains a challenge, we need the HTA process to find a way to</p>

		include qualitative statements about improvements in QoL brought about by a new drug.
General	Click here to enter text.	acknowledgement acknowledgement that especially in the case of rare and less common cancers that the patient has a unique level of knowledge to bring to the debate acknowledgement that at the moment, many man hours spent by patients and patient groups over a considerable time period is in no way measured or acknowledged
Click here to enter text.	Click here to enter text.	Click here to enter text.
Click here to enter text.	Click here to enter text.	Click here to enter text.

To submit your comments, please email this form to: PPIConsultation@nice.org.uk

Closing date: Tuesday 28th February 2017

If you are interested in getting involved in NICE's work in the future, please tick this box X. Please make sure you have included a contact email address at the top of this form. By ticking this box you consent to NICE contacting you.

PLEASE NOTE: NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of the Institute, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.

ⁱ 'Speaking up for patients- Patient organisation involvement in Health Technology Assessment, with a focus on Patient and Clinical Engagement at the Scottish Medicines Consortium
<http://www.cancer52.org.uk/wp-content/uploads/2014/09/PACE-SMC-Report-LB-comments-formatted.pdf>

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