

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

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

Comments form

Name:	Sarah MacFadyen
Role: (Please select from list)	<p>Medical or dental professional <input type="checkbox"/></p> <p>Nursing or midwifery professional <input type="checkbox"/></p> <p>Allied health professional <input type="checkbox"/></p> <p>Scientific or technical professional <input type="checkbox"/></p> <p>Pharmacist <input type="checkbox"/></p> <p>Healthcare support services <input type="checkbox"/></p> <p>Public health professional <input type="checkbox"/></p> <p>Social care professional <input type="checkbox"/></p> <p>Care support services professional <input type="checkbox"/></p> <p>Manager <input type="checkbox"/></p> <p>Research or academic professional <input type="checkbox"/></p> <p>Admin or clerical professional <input type="checkbox"/></p> <p>Student <input type="checkbox"/></p> <p>Patient / service user <input type="checkbox"/></p> <p>Carer <input type="checkbox"/></p> <p>Other <input checked="" type="checkbox"/> Please specify Third sector representative - British Lung Foundation</p>

<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>Sarah.macfadyen@blf.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>The British Lung Foundation receives some funding from a range of corporate sources, including the pharmaceutical industry to deliver specific projects.</p>

Consultation question	Response to consultation question
<p>1. What are your views on our stated principles for involving lay people* in developing our guidance and standards? (Page 7)</p>	<p>Please do not paste other tables into this table, because your comments could get lost. Please type directly into this table.</p> <p>The BLF is generally supportive of the principles of this draft guidance. We are very pleased that NICE is making this work a priority as we believe all of NICE's work can benefit from meaningful inclusion of, and consultation with, patients, carers, and others affected by health conditions or disability.</p> <p>Our overall recommendation is that there should be a redefinition of what NICE means by 'lay members'. We believe that patients and carers should be treated separately from representatives of patient groups, such as the BLF, for the purposes of NICE committee recruitment. Charities and patient groups should be represented on committees and make a significant contribution, but they are not a replacement for hearing from individuals who have direct lived experience. Our experience of working with NICE committees has been that we are often in competition with patients for a small number of lay member places. We do not feel this is appropriate or fair to patients. We therefore recommend that on each NICE committee, lay member places are reserved separately for patients/carers and representative groups.</p> <p>We welcome the commitment to present all guidance in accessible language. We would also like to reiterate the importance of writing consultation documents in 'plain English' so they are accessible to as wide a group of people as possible. We feel that this consultation in its current form does not lend itself to being easily understood and engaged with by patients and the public.</p>
<p>2. What are your views on our plans to standardise the approaches to how we engage with and</p>	<p>We support this plan. Standardisation is welcome to increase transparency and the ability of patients and charities to engage with NICE across a range of issues.</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.

<p>involve lay people across our guidance and standards programmes? (Page 8)</p>	<p>However, we would highlight the fact that some conditions or topics for consideration will be complex and patients may need to be engaged in different ways. We would not want this to become a 'one size fits all' process, so we would urge NICE to ensure appropriate flexibility to meet the needs of patients.</p>
<p>3. What are your views on our proposal to involve lay people earlier and keep them involved throughout the development process? (Page 9)</p>	<p>We strongly support efforts to engage patients and the public early in the scoping phase. We would also advise involving patients in the selection of topics, as they will be best placed to highlight where current systems and treatments are not meeting their needs.</p>
<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>We support these plans.</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>We support the proposal to recruit a pool of people who can be called upon to comment on specific conditions. However, NICE must be sensitive and clear with patients about the chances of them being called upon and what they will be asked to do in this event. There is a risk that patients who are recruited but not called upon to contribute may become disengaged.</p> <p>NICE should also bear in mind that some conditions have a high risk of mortality or rapidly changing disability. For these conditions, efforts must be made to involve patients and request their views in a timely manner.</p> <p>We are pleased to see a commitment to ensuring diversity. We would be keen to see more information as to how NICE will do this.</p> <p>NICE should look to the examples of many charities which have set up effective patient engagement groups. The BLF would be happy to share learning from our Patient Think Tank, which advises on a range of activities the charity carries out, including the development of policy positions.</p> <p>We strongly support proposals to allow charities and patient representative groups to recommend patients to take part in NICE committees. However, we believe this should happen alongside standard recruitment, not only in the event that recruitment has failed. This will increase the chances of NICE recruiting patients who are experienced and able to participate in committees.</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>We agree that it is highly important for lay people to receive feedback on the impact their input has had. This will help to increase confidence in the process and ensure patient recommendations are addressed.</p> <p>We would recommend that NICE follow the example of the Scottish Medicines Consortium and publish a summary of lay people's views and the impact of their evidence with each decision.</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>We welcome increased and improved use of social media to reach patients.</p> <p>However, we would urge NICE to consider digital exclusion. Certain communities, including older people, socially deprived communities, and people whose first language is not English, may not be as likely to engage through social media. Alternative approaches must be made to ensure NICE are reaching out to these groups.</p>
<p>8. What are your views on increasing NICE staff awareness and knowledge of public involvement? (Page 12)</p>	<p>We welcome efforts to increase awareness and knowledge of public and patient involvement amongst all NICE staff.</p> <p>NICE could consider offering shadowing programmes or skill sharing opportunities with external groups, such as health charities, who have experience and a positive track record of patient engagement.</p>

General comments on the consultation paper		
Number of the section your comment primarily relates to (please enter only one) Indicate ' <u>general</u> ' if your comment relates to the whole document	Other section numbers your comment relates to	Please insert each new comment in a new row
General	Click here to enter text.	<p>We recommend that NICE ensure involvement of carers as well as patients. This is particularly important for irreversible or terminal conditions where carers will be well placed to advise on the full trajectory of the illness and how they have experienced health services and treatments throughout.</p>

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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 . 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.

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