

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

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

Comments form

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<p>Email address:</p>	<p>holly.dawson@nationalvoices.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>In the past three years we have received donations from three corporate donors (Baxter, Pfizer and Merck, Sharp & Dohme), which contributed to the costs of our annual members' conference. They did not influence or play any part in the conference. There was no commercial benefit to them or endorsement of these funders by National Voices.</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 7 improved principles set out in the draft document go some way towards ensuring that lay people are meaningfully involved in decision-making during development of new guidance and standards. We particularly welcome the fact that the principles cover involvement at every stage of guidance development, from choosing topics to dissemination.</p> <p>Our main concern about the principles for involvement is that they are all focused on procedure, with no mention of an underlying value-base. Whilst procedural principles facilitate standardisation of good quality involvement across the organisation, a shared set of values is key to creating 'an organisational culture that puts lay people at the heart of NICE's work' (paragraph 49). If the drive to co-produce is not genuine, it runs a greater risk of being tokenistic and unproductive, for both lay person and the organisation.</p> <p>We recommend adding values-based principles to the current set of principles, or drafting a separate set of values which underpin the procedural principles. The C4CC Co-production Model (http://www.partnersinsalford.org/engaging-with-marginalised-groups.htm) and the 4Pi National Involvement Standards (http://www.nsun.org.uk/assets/downloadableFiles/4PiNationalInvolvementStandardsFullReport20152.pdf) outline evidence-based values which could be replicated for this purpose. We would particularly like to highlight the need for a value about respect and equality between lay person and NICE staff; "the key point is respect and equality in working relationships... the service user is on the same level as staff, otherwise (involvement) doesn't work" (4Pi, page 14). The C4CC model value 'A commitment to sharing power and decisions with citizens' would be appropriate.</p> <p>This broad concern aside, there are a few specific amendments we would suggest making to the draft principles of involvement.</p> <p>First, principle 3 states that a minimum of 2 lay people should be on each committee. We think that this should be reworded so that a minimum of 2 lay people are in attendance at each committee meeting. This</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>would entail recruiting say 4 lay people to the committee to take absences into account. Patients and carers are more likely to be unable to attend meetings, sometimes at the last minute, because of appointments, ill health, or caring responsibilities.</p> <p>Holding a meeting at which no lay person is present should of course be avoided at all cost, but it should also be a principle that no meeting takes place with a solitary lay person. Lay people can feel intimidated by the professionals around them, quashing the potential of their presence (Linhorst et al., 2002) but this effect is mitigated if they are supported by other 'non-professionals'.</p> <p>Having more lay people on a committee also increases the opportunity for diversity. A mix of people with lived experience, carers, and voluntary sector representatives can be involved, allowing both insight (a detailed perspective of one or two individuals' own experiences) and oversight (a perspective from a voluntary sector representative who can generalise from the experiences of many). Furthermore, it allows greater capacity for involving people from less-heard communities. Increasing committee recruitment from 2 to 4 lay people would allow for the selection of a wider range of lay perspectives, and the potential for guidance and standards to be more relevant to the whole of the population they apply to, not just the mainstream.</p> <p>Second, principle 5 states that guidance and standards should be written clearly and comprehensibly. We recommend that this principle is extrapolated to include all communications from start to finish of the lay involvement process, including, but not limited to, the final guidance or standards. All documents should have a plain English and easy-read alternative to ensure that lay members, who will not have a clinical background, can understand content and participate in discussions fully. Plain-English texts should apply throughout the recruitment process, including at application stage to ensure that as broad a spectrum of patients, carers and voluntary organisations are able to apply. It might also be helpful to frame the principle in terms of overall accessibility rather than clarity of written information, as writing clearly is just one variable of many to consider when making information accessible to all groups of people. The NHS England Accessible Information Standard (https://www.england.nhs.uk/ourwork/accessibleinfo/) could be an appropriate benchmark.</p> <p>In relation to accessibility, it is important to consider the population group(s) that the guidance or standards will be relevant to, e.g. 'easy read' information for people with learning disabilities. This should extend beyond the guidance and standards themselves to the accessibility of the whole involvement process, including recruitment. For example: holding meetings in accessible locations for people with physical disabilities; finding an alternative to the traditional meeting format for children and young people, and recruiting and facilitating involvement offline for older people and people without internet access. The use video conference technology should be considered to involve lay-members based far from London or</p>
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	<p>who, due to caring responsibilities or other reasons, would be unable to commit to physically attending monthly meetings in central London.</p>
<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>	<p>It is an excellent goal to standardise terminology used across NICE programmes, as variations in terminology can cause significant confusion, and improving in this area will increase understanding of the ways to get involved in NICE's work. It is recommended that lay people are included when choosing this terminology, as semantics can be a matter of great contention in this area. There is, for example, a significant perceived difference in the meanings of 'involvement' versus 'engagement'. It is true that what is deemed 'correct' terminology is in constant flux, but by employing terminology currently used by the patient movement there is a lesser chance of misunderstandings.</p> <p>It is, in principle, a good idea to involve the same lay people throughout the development of a piece of guidance or standard. In line with our response to question 1, this again increases the need for more lay people to be involved, to allow for dropout.</p> <p>We would suggest one addition to the standardised procedure for lay involvement across NICE: a standard rewards and recognition policy for people with lived experience and carers (i.e. people who are not being paid by another organisations for their work in partnership with NICE).</p> <p>Covering expenses ensures that people who give up their time and expertise to contribute to guidance and standards are not 'out of pocket' for doing so. These expenses include obvious costs like travel and accommodation, but should also include replacement care (for carers and parents of young children) and the cost of measures taken to make involvement possible, for example a support worker or BSL translator. Bear in mind that travelling can be more difficult for people with disabilities, so overnight accommodation is sometimes necessary and should also be covered by expenses.</p> <p>Paying an additional 'reward' to lay people is fair, in that their expertise and efforts are equally as valuable as those of paid professionals. Ideally the reward should be equivalent to what NICE staff members are being paid for the amount of time worked. There are some extra factors to consider when paying a lay person who is receiving benefits. If they are rewarded 'too much', they risk losing their benefits. SCIE has a useful guide about paying people who receive benefits (http://www.scie.org.uk/publications/ata glance/ata glance50.asp).</p>
<p>3. What are your views on our proposal to involve lay people earlier and keep them involved throughout</p>	<p>We approve of the suggested measures to involve lay people earlier in the process of developing guidance and standards. NICE must ensure that this aim to involve people earlier doesn't result in rushed, flawed recruitment drives, or last-minute requests for lay people to attend meetings. Involving people early in development should instead mean beginning recruitment much sooner - this will be aided by the planned 'pool of lay people' which will already have been identified.</p>

<p>the development process? (Page 9)</p>	<p>We recommend that 'involving people right from the start' is used instead of 'involving people earlier', as the word 'early' is vague and could lead to misconceptions about when lay people's involvement in developing guidance and standards should begin.</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 ask for greater clarity on this section in the proposal. We are unsure why it is necessary to ask manufacturers to provide information on people's experiences of care when the manufacturers' selections of experiences to share would be highly subject to bias. We believe that evidence gained from independently collecting experiences, through expert witnesses or by using the extensive networks of the voluntary sector, would be far more valid.</p> <p>This aside, it is important for some population groups that people beyond the individual receiving care are contacted about experience of care. For example, babies and young children will be unable to directly to feed back on their care, so it is essential that their families are included in any analysis.</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>Recruiting a pool of specialist lay people, as well as increasing efficiency, would give NICE the opportunity to build in different levels of engagement on a single project. According to the 4Pi paper, offering a range of ways of being involved attracts a greater number and variety of people. To briefly illustrate how this could work:</p> <ul style="list-style-type: none"> - 2-4 people are involved at a high level, e.g. those recruited to sit on a committee - A small group are involved at a slightly lower level, e.g. group of relevant people from the pool of lay people to act as expert witnesses - The whole pool of lay people are kept in the loop about the project and given small opportunities to be involved, e.g. comments on draft guidance - A large number of people are involved superficially, e.g. through polls or comments on social media <p>Paragraph 36 in the proposal, maintaining diversity, is very important to the success of the recruited pool of lay people. Rather than being passively maintained, diversity should be positively sought through outreach programmes. This will require some level of experimentation in terms of which publicity methods are effective for different less-heard groups, alongside careful monitoring of currently recruited lay people to ensure that less-heard groups are well represented. Working with voluntary and community organisations can be effective for targetting specific populations. SCIE (http://www.scie.org.uk/co-production/people/) and Salford City Partnership (http://www.partnersinsalford.org/engaging-with-marginalised-groups.htm) have useful resources about engaging different groups.</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>The process of gathering and acting upon feedback is instrumental to the continuous improvement of NICE's patient and public involvement programme. We therefore recommend that this section of the proposal is expanded upon to ensure that a) lay people are encouraged to participate again as they can see the clear impact of their efforts, and b) NICE is fully aware of the strengths and flaws of the involvement programme, and can continue to improve.</p> <p>It is difficult to assess the success of a lay person's involvement when the criteria for success are not apparent from the outset. We think it would be useful for both lay people and NICE members of staff if the formal feedback process was joined by a formal induction process prior to involvement. This would be an opportunity to:</p> <ol style="list-style-type: none"> 1. Ensure that the lay person understands the project. This includes explaining the purpose of involving lay people, as recommended by the National Involvement Partnership Review of Resources (see page 15 of the 4Pi paper). Drawing up a job or role description can be helpful. It would also be useful to share dates of meetings and other practical information (e.g. rewards and recognition) well in advance. 2. Lay down a 'foundation of shared principles and values' (4Pi, page 14). If lay people and NICE staff members have an honest discussion about what they each expect of the other, it starts the project off in a place of openness and transparency and will reduce scope for disagreement further into the project. 3. Determine criteria for successful involvement of the lay person in that project. These don't need to be rigid KPIs that will be actively measured, but should be a set of goals that cover both impact (is the lay person's voice reflected in the final product?) and the person's experience of the involvement process. This is a chance for NICE staff members to manage expectations and be honest about the limits of involvement (4Pi - 'clarity and transparency needs to be shared about the potential for involvement and influencing, as well as the limits of influence'). <p>With regards to the feedback process, we would advise that NICE investigate a number of feedback mechanisms to sit alongside the survey, as each is more or less successful in different situations, often depending on the population group being surveyed. The King's Fund review of feedback in maternity services offers analysis of a large variety of feedback mechanisms, many of which could be applied to this context.</p>
<p>7. What are your views on our proposal to make better use of social media, alongside our existing</p>	<p>Social media is a great tool to reach large numbers of people with relative ease. It could be particularly helpful in increasing engagement among young people. As well as advertising opportunities to be involved at an in depth level, social media could be used to gather snippets of 'superficial' information from a large number of people (e.g. using polls or asking for comments).</p>

<p>communication channels? (Page 11)</p>	<p>It is prudent, though, to be aware of the people who tend not to use social media and who are therefore likely to be missed from NICE's involvement attempts. The Department for Culture Media and Sport's report 'Taking Part focus on: social media' (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/519678/Social_media_-_FINAL.pdf) found that 29.6% of adults in England hadn't used social media in the past year. Social media users are disproportionately young adults, and people with disability and long-term illness are underrepresented.</p> <p>For these reasons, it is sensible to look into other means of recruitment, publicity and engagement that can complement an increased use of social media. The networks of people with lived experience and carers created by voluntary and community organisations are an underestimated resource; tapping into these could be a good place to start.</p>
<p>8. What are your views on increasing NICE staff awareness and knowledge of public involvement? (Page 12)</p>	<p>As highlighted in our answer to question 1, successful patient and public involvement depends on an organisational culture in which involvement of lay people is genuinely seen as crucial to obtaining good quality outcomes. Promotion activities and training as outlined in the proposal could help generate such a culture, especially if lay people have a prominent role in this promotion (e.g. blog posts written by lay people as well as NICE staff members).</p> <p>Training sessions about the importance of lay involvement and best practice in doing so should be delivered to both new members of staff and all existing members of staff. Though in the draft proposal it says that the latter shall be considered, we would argue that it is vital to train existing members of staff as well as new; if new staff enter a working environment which doesn't already welcome or fully understand patient and public involvement, they might find it difficult to incorporate involvement without the support of their colleagues. In addition, if involvement is to be the responsibility of everyone working in the organisation then it is equally as important to train front-of-house staff as senior leaders, as all of these people will have some direct or indirect contact with the lay people being involved.</p> <p>These training sessions should ideally be co-produced and co-delivered with lay people (those who have significant experience of working with NICE) and staff members. This means that a) lay people can demonstrate the positive impact that they have had on past guidance and standards, and b) factors that are important to lay people partnering on projects are embedded in the mindset of staff members from the start.</p> <p>Promotion and training should aim to instil values and behaviours like those set out in C4CC's Co-production model: it is recognised that people with lived experience of a condition are often best placed to</p>

	advise on the support and services that will make a positive difference to their lives; everyone involved in a project is valued and respected, and the responsibility to co-produce is owned by all.
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General comments on the consultation paper		
Number of the section your comment primarily relates to (please enter only one) <small>Indicate '<u>general</u>' if your comment relates to the whole document</small>	Other section numbers your comment relates to	Please insert each new comment in a new row
General	Click here to enter text.	<p>It is extremely important for NICE to consider the methods by which they will support the large group of lay people recruited to take part in projects. In the same way that NICE staff members will be offered training on co-production and working with lay people, it makes sense to offer training to lay people on co-production and working on NICE projects. This could take the form of an e-learning resource, as it would be both cost- and time-efficient for NICE, and convenient for the lay person. Such a resource would need to also be available in hardcopy and accessible versions.</p> <p>The 4Pi National Involvement Standards suggest that support offered to lay people covers administrative support, supervision, and emotional support. With regards to the latter, a peer support system among lay people could be effective. This could include one-to-one support between experienced lay people and those being involved for the first time, and groups for all lay people involved in NICE (e.g. an online forum or Facebook group).</p>
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Closing date: Tuesday 28th February 2017

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