

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

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

Comments form

Name:	Tara Finn, Diabetes UK
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 Policy Officer</p>

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<p>Email address:</p>	<p>Tara.Finn@diabetes.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>	

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>We welcome the seven principles and their aims to involve lay individuals with diabetes throughout the NICE process. However we are concerned that the principles do not define the value of lay people’s involvement and how it will be weighted and used in the development of guidance. We would not want lay involvement to merely be tokenistic but demonstrate the value to both the individual involved as well as to the development of guidance. How lay people’s experiences and involvement impact the development of the guidance needs to be transparent.</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>We agree with there is a need to standardise how lay people are involved across NICE programmes. We hope that once the standardisation has been agreed for guidance and quality standards that this is also applied to the rest of NICE products where lay individuals are involved such as the citizens council and office of market cost.</p> <p>We also think that the terminology and language used should be standardised and plain English used where possible, as this is in area that causes confusion. Alternatively an introductory workshop for all lay members should be incorporated so that they have an understanding of the terminology before they are involved in any NICE processes.</p> <p>We have heard that some scoping workshops for some common health conditions such of diabetes do not always have a patient representative or that scoping workshops for such conditions are not needed as it is felt the needs of a particular patient populations are understood. Standardisation on this issue would be welcome. The current situation is unfair as people’s experience of their condition are transient and should not be assumed by healthcare professionals; there is</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>variation within a medical condition such as different type of diabetes and age of diagnosis.</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 support the view that lay people should be involved earlier in the development of guidance and standards. What stage do you envisage 'earlier' being?</p> <p>In addition early involvement should not mean that recruitment of lay people is rushed. We feel that rather than being involved earlier that lay people should be involved the beginning of any process and stay involved for the duration of guideline's development.</p> <p>We feel that multiple lay people being involved in the process will help ensure representation of lay people in the case of sickness absence or doctor's appointments. For long term conditions that have a dynamic effect on an individual such as diabetes, lay people representatives should also reflect this For example a newly diagnosed individual's experience of diabetes may be very different to a person who has been living with the condition for a decade.</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>At the moment the process of collecting and using people's experiences of care seems very ad hoc. From our point of view as a patient representative organisation we feel restricted in how we can get the get the best patient feedback to you.</p> <p>For example, we are often asked to comment on new technologies or guidance, to do so we have to first sign a confidentiality agreement without knowing what we will be asked to comment on. Therefore when the documents are sent through we do not necessarily have an appropriate individuals assigned to the confidentiality agreement so are unable to give a full response. Had the initial brief been clearer on who the technology/guideline was aimed at, we would have been able to organise feedback from more relevant individuals.</p> <p>We propose that the time frame for feedback be longer. Patient organisation would have time to gather appropriate patient representatives</p> <p>Also the format in which the feedback is collected should be moved to an online submission portal. This would allow comment on a particular piece of guidance (with a confidentiality agreement included before people can start there feedback)</p>

to be easier and for patient representative organisation to more effectively share with colleagues and patient groups would be able to give rich feedback.

Explanation of how lay people's experience are of value and considered in the development of NICE guidance alongside the QALY, studies and modelling is needed. Currently it is felt that it does not have the same weight as other research findings. Lived experience testimonies need to be referenced.

Other ways in which patient experiences can be fed into the development of NICE guidance.

1. Accepting evidence gathered by patient representative groups such as patient survey data or summary reports.
2. To better utilise the EQ-5D, although not sensitive enough for all cases of gathering patient experiences, it is the best tool at our disposal.
3. NICE should include the challenges faced by people who have the condition perhaps through value based assessments of technologies. This was an area that NICE explored in 2014. Although a contentious issue perhaps Value based assesment needs to be revisited. To use QALY with consideration of the VBA QALY and patient experience inforamtaion would give a more wholesome picture of health, social care and well-being of a patient population.
4. A standardised approach to patient involvement should also allow for flexibility in where patients are involved. For example if there is an area of uncertainly raised in the guidance development process, patients experience may be able to help. NICE should signpost these areas of uncertainty to patient organisations and patient representatives as an opportunity for their experience to be of value in determining the direction of the guidance.
5. In feedback forms, patients should be involved in the design of survey and questionnaire to ensure they are impartial rather than tailored to a particular conclusion.

The Candairan pCODR model uses a expert review committee, the pCODR Expert Review Committee (pERC). Committee members examine the clinical and economic information provided by the guidance panels, as well as patient

	<p>advocacy groups to formulate a recommendation. The Committee involves specialists, physicians, pharmacist, economist and patient members that stay throughout the technology.</p> <p>There are five criteria that Committee consider: four of which are similar to current NICE considerations. However the criteria element 'Alignment with Patient Values' means the committee has to make an assessment of the technology after considering information on patient values brought to light by patient advocacy groups input sought at beginning of the review. This is a model worth further exploration by NICE to assess whether this model allows for lay people's experience to be values and have impact on the development of a guideline.</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>The proposed changes to recruitment of lay people offers both parties a more effective partnership when involved in the development of NICE guidelines. The different types of lay members' offers a tiered levels of engagement, therefore the opportunity for a greater variety and number of people to be involved. This will help ensure views and lay people's experience are more representative of the patient population. The terminology used to describe the different type of lay members should avoid jargon terms and perhaps be graded in terms of the depth of involvement. Each position should have a role description, dates of meetings, rewards, recognition, what the limitations of the role and made aware that some information is restricted and a confidentiality contract may have had to be signed.</p> <p>Social media should be used to notify people of vacancies and opportunities to comment. It should be noted that that there are still many people who do not used social media as, notable the older age groups. Therefore recruitment through other means should be considered such as advertising through patient representative groups. Patient organisations can help with the recruitment and support of lay members through the NICE. Patient organisations would be able to help recruit more marginalised patients who may not be aware of NICE recruitment process.</p> <p>Due to the nature of NICE and its products, training or introductory workshops to all lay people involved should be offered. If this type of training is not sustainable,</p>

	<p>training of patient organisations who help with recruitment could be offered so that they can train recruits. Or a toolkit on how lay people are involved the development of guidelines: what to expect, how they will be involved, how their involvement will be valued, staff contact, signposting to patient representative groups who could offer them support, glossary of terms, objectives of NICE.</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>Formal feedback is essential for lay people to understand the impact of their involvement and experiences. Given that lay people are sharing personal experiences and potentially not used to speaking in such formal settings, feedback and thanks should be equally personal rather than through a computer.</p> <p>We would advise that NICE look at multiple ways of giving feedback to sit alongside a survey, depending on the population group being surveyed and level of involvement. Lay people should be involved in devising any survey.</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>The use of social media would be useful to, promote recruitment of lay individuals, give updates on guidance development and raise awareness of opportunities to contribute to guidance development. However it is not always possible to direct how social media posts and requests are used by the public. The quality of evidence from twitter and Facebook would be weak and does not allow for thought.</p> <p>The development of a NICE topic forum for a particular piece of guidance would be a better platform and one that could be monitored by NICE. Themes in forum participants' discussions could be taken and considered in guidance development. If there was an area of uncertainly the issue could be proposed as a discussion point to hear suggestions.</p>
<p>8. What are your views on increasing NICE staff awareness and knowledge of public involvement? (Page 12)</p>	<p>It is essential that all staff are aware of how to involve the public. This is key for a culture change in NICE to re-assess the value put on lay' individual's experiences when developing NICE guidance and standards. Staff members need to be made aware of and understand the importance of lay people's involvement in the</p>

	<p>development of NICE guidance, for it will become a standard practice to consider the views of lay people and place greater value on their experiences.</p> <p>We believe that this should stem from examples of how lay people involved in the process have had an impact on the development of guidance. We suggest that NICE should use case studies from the current process of how lay people's experiences have influenced guideline development decisions.</p> <p>We have heard anecdotally that Committee members often disregard the views of lay people. Lay people have also felt their contribution discounted as they are not from a medical background. This is despite living with the condition on a daily basis. Being a non-healthcare professional should not disqualify or limit the value of a lay person's contribution. Especially as in reality we are all patients even the most eminent healthcare professionals.</p> <p>The fact that committee members often know each other well compared to the lay people also needs to be addressed. Perhaps through informal pre-meeting gatherings in less daunting settings for people to understand each other's perspective before the formal committee meetings begin. Alternatively lay people to sit with a committee throughout the development of a guideline so they are considered at the same standing.</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, including front-of-house staff, senior leaders, and all those who will have some direct or indirect contact with the lay people.</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>
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General comments on the consultation paper

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

Closing date: Tuesday 28th February 2017

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