NICE National Institute for
Health and Care Excellence

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE
Improving how patients and the public can help develop NICE guidance and standards

Comments form

Name:	Dr Andy Clempson, Senior Research Policy Manager, Association of Medical Resarch Charities
Role: (Please select from list)	Medical or dental professional ☐ Nursing or midwifery professional ☐ Allied health professional ☐ Scientific or technical professional ☐ Pharmacist ☐ Healthcare support services ☐ Public health professional ☐ Social care professional ☐ Care support services professional ☐ Manager ☒ Research or academic professional ☐ Admin or clerical professional ☐ Student ☐ Patient / service user ☐ Carer ☐ Other ☐ Please specify Click here to enter text.

Organisation type: (Please select from list)	Primary care ☐ Community care ☐ Secondary care ☐ Tertiary care ☐ Long term residential care ☐ Local authority / Healthwatch Local ☐ Clinical Commissioning Group ☐ Commissioning Support Unit ☐ NHS England ☐ Public Health England ☐ National regulator / advisory body / arm's length organisation (non departmental government body) ☐ University / college / school ☐ Pharmaceutical / medical technologies ☐ Advocacy and patient / service user support group ☐ Other ☒ Please specify Charity
Email address:	a.clempson@amrc.org.uk
Have you or your organisation received any payments, grants or other funding from the pharmaceutical industry in the past three years?	No

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)	Overall we support the proposed principles for involving lay people in developing NICE guidance and quality standards. In relation to the fifth principle that 'guidance and standards are written clearly and comprehensibly to inform people about the care available to them' we would note that in some circumstances particular consideration and efforts will have to be made to ensure that the information is accessible and/or understandable by the relevant patient population. We encourage NICE to work with a broad range of patients and charities to develop these materials - AMRC could act as conduit to the 140 medical and health research charities we represent.
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)	The proposals appear sensible, however, they are very high level and it is unclear 'how' they will be put into practice. For example, does 'building on areas of good practice within NICE' mean that good practices will be identified and systematically incorporated into NICE internal process guides, SOP's etc? We understand that these processes are yet to be formally mapped out, but we encourage NICE to consider how best to work with a broad representation of patients and charities so that a standardised approach is appropriately inclusive.
3. What are your views on our proposal to involve lay people earlier and keep them involved throughout the development process? (Page 9)	The principle of involving people early is welcomed. However, the proposals lack clarity over what 'earlier' actually means in practice. Does it mean, for example, that patients and the public will always be involved at the very earliest stages of all substantive discussion, including on selection of topics and scoping? If not, it should be clarified why patients and the public would not be included at the earliest

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* 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.

	stages and the rationale behind more nuanced approaches should be explained. This is important for fostering accountability and transparency in NICE's processes, and thereby building public trust.
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)	The principle of being clearer on how information on people's experiences of care and services are taken into account is welcomed. However, in relation to the specific proposal to ask manufacturers to provide information on people's experiences, we would be interested to know more detail around what the expectations might be (i.e. what evidence, how much, how will the manufacturers access such evidence, and will NICE guidance in relation to expectations be developed?).
	Many manufacturers work with patient groups and medical research charities to better understand diseases and conditions, thereby informing and providing evidence in support of R&D activities. However, we are unclear if the draft NICE proposal signals a step change in expectations which might drive significantly increased interactions (and need for resources) with patients and medical research charities in particular. If this is the case, clarity over these expectations is essential, and a managed implementation would be helpful for all partners to understand what information is required by when, and for capacity to developed to manage this accordingly. It should also be noted that most organisations have strict policies on their engagement with third parties, taking a carefully considered approach for each request. While in the most part charities are willing to collaborate with a broad range of industry partners, there may be some circumstances where such collaborative working is not possible.
	Finally, there may be some unforeseen barriers to increased engagement between industry, charities, patients and lay people. For instance, there may be an increase in conflicts of interest for patients and lay people who have provided advice to industry who are also involved in NICE's work. Guidance and clarity is required to ensure that all interested parties know about the potential repercussions resulting from conflicts of interest so that patients and lay people can make informed choices over where they would like their involvement focussed.

	An additional potential barrier may be over-burdening patients and charities with repeated requests for advice. This is particularly true for rare diseases where the patient population is much smaller and therefore efforts are concentrated around a small group of individuals. Care should be taken to ensure a streamlined and coordinated approach is taken so that patients do not feel 'pestered' or pressurised into being involved - particularly if they have made their preferences clear that they do not wish to be contacted.
5. What are your views on our proposed new approaches to recruiting lay people to our decision-making bodies? (Page 10)	The proposed new approach to recruitment is suggested to be more efficient, appears sensible, and is therefore welcomed. However, the 'pool' approach must take into account the needs of the patients/public who are offering to provide their knowledge and experience. For example, once recruited, the patients and public should be made to feel very much members of an active and valued 'pool' (i.e. they are inducted into the work of NICE, trained in their roles, and kept actively engaged through regular communications throughout the period of deployment to the 'pool'). Additionally, the number of individuals deployed to a 'pool' who do not subsequently get appointed to a specific task, or in some other way have their contribution recognised, should be kept to an absolute minimum.
6. What are your views on our proposal to introduce a formal feedback process for the lay people working with us? (Page 11)	These proposals appear sensible.
7. What are your views on our proposal to make better use of social media, alongside our existing communication channels? (Page 11)	These proposals appear reasonable and sensible although it should be emphasised that in some health conditions, or within certain demographics within a health condition, there are wide sections of society who do not engage with social media, or perhaps require different technological needs to communicate. It is acknowledged that such people can sometimes be hard to reach through any form of communication media, but we recommend that NICE engage with the relevant charities to understand appropriate communication channels and explore untapped opportunities for collaborative dissemination.

8. What are your views on increasing NICE staff awareness and knowledge of public involvement? (Page 12)	These proposals appear reasonable and are supported but we stress that organisational culture change is notoriously difficult to achieve. Consequently it is important that clear objectives are set and progress against these objectives is monitored regularly. We are unclear how NICE will evaluate the progress they are making towards such cultural change and would welcome additional details on this. NICE could for example measure cultural change across the following criteria: - Consultation: measures may include the number of people who have been asked to feedback throughout NICE's processes, the number of diseases or conditions where consultation was sought, diversity metrics, the effect that the consultation had on outcomes (noting the importance of measuring baseline data). - Collaboration: this may involve measuring levels of engagement throughout all of NICE's work, collection of data to demonstrate whether collaboration led to a measurable change in NICE processes - such as earlier engagement, the introduction of new mechanisms or streamlining of existing NICE processes. - Partnership: measures could look at whether patients have an equal level of influence on NICE processes - are patients and the public involved at all stages? Are there other steps that NICE could take to ensure that patients have an equal voice? Do patient and the public have an opportunity to feedback to NICE where their involvement has been meaningful, and where improvements might be made? These three levels of criteria were developed by Cancer Research UK. Throughout these measures, NICE could also develop a series of case studies that show the value of patient and public involvement. This could form a central pillar of staff training to emphasise the critical role of patients and the public throughout NICE's work. NICE may also wish to consider whether more meaningful collaboration with medical research charities could drive a wider cultural change towards patient and

		public involvement. Many charities have their own programmes designed to increase such activities - e.g. stakeholder engagement forums, patient focussed seminars/conferences, patient and public ambassadors, patient registries, and charity-driven surveys/questionnaires to their communities. More meaningful collaboration would send a strong signal throughout NICE and the wider research community that patient and public involvement is recognised as a crucial process throughout the research process - and to patients that they have opportunities to be involved at every stage.

General comments on the consultation paper		
Number of the section your comment primarily relates to (please enter only one) Indicate 'general' 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.	There has been a growing recognition of the importance and value of the patient and public perspective in informing the processes of discovery, development, regulation and adoption of new medicines and healthcare products. It is acknowledged that this is an evolving and complex area which can provide significant challenges. However, the NICE initiative is welcomed as a contribution to improving patient and public input to one very important element of the healthcare environment. Overall, the proposals developed by NICE appear sensible and pragmatic and are therefore to be welcomed. However, we note that little detail is provided in relation to some of the proposals. Clarity would be helpful in these areas, as noted in the sections above.
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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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