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

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Contents

Summary

NICE is reviewing its approach to involving lay people (in this context, people who are not health or social care professionals) in developing guidance and standards.

We have talked to our stakeholders (both inside and outside NICE) and reviewed studies on best practice for involving lay people.

We have used the information we gathered to develop improved principles for engaging and involving lay people.

We have also proposed specific changes, which are:

- Standardising how we engage with and involve lay people across NICE's guidance and standards programmes.

- Involving people earlier and keeping them involved throughout the development process.

- Being clearer on how we find and take account of information about people's experiences of care, and their experiences of their condition and its treatment.

- Recruiting a broad pool of people (including people with knowledge and experience of specific conditions or services) who can be drawn on as needed to join decision-making bodies.

- Introducing a formal feedback process so that people who help develop our guidance and standards are aware of the impact of their contribution.

- Making better use of social media to communicate with people about our guidance and standards, and to make it easier for them to communicate with us.

- Reinforcing the message among NICE staff that involving people is everyone's responsibility.

We are seeking your views on these proposals. Our consultation will run from 1 December 2016 to 28 February 2017.

The topic in more detail

1. NICE seeks to improve the health and wellbeing of the population through our evidence-based guidance and quality standards. We recognise that people who use health and social care services also have an important role in improving the health and wellbeing of the population. Therefore, as part of our core values, we work with patients and members of the public (lay people) so that our guidance and standards:

    - take direct account of the perspectives of people who use health and social care services

    - are available to lay people so they can make informed choices about the services, interventions, care and treatments available to them.

2. Patient and public involvement is high on the national policy agenda. The patient activation programme at NHS England aims to help people better manage their own health and have a say in their care. The recently published Accelerated Access Review calls for early and ongoing involvement of lay people in the development of medicines and technologies.

3. When we develop our guidelines and standards, we take a standardised and evidence-based approach to involving lay people, and seek to uphold internationally agreed values and standards on participation and engagement (Health Technology Assessment international).

4. As an evidence-based organisation, we want to make sure that our approaches to engaging with and involving lay people are in line with best practice. We also want to make sure we take a collaborative approach to making recommendations and provide a useful and effective experience for the lay people who work with us.

5. We have decided to review our overall approach to involving lay people in developing our guidance and standards. We have investigated several evidence sources to determine best practice, and considered how our current approaches compare (appendix A). We have used this evidence to propose new principles and ways of working, which we are now consulting on.

A note about language

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 for voluntary and community sector organisations; and people who have an advocacy role.

We acknowledge the limitations of the term 'lay people' and the inherent power imbalance it appears to reinforce. However, we use this term in the absence of any alternative single term that covers all the relevant groups and people.

How can lay people get involved in NICE's work at the moment?

6. NICE has various opportunities for lay people to participate in, engage with and get involved in our work. For the purposes of this consultation paper, the following definitions are used:

    - Participation: NICE's overall approach to taking account of the views of lay people and the organisations that speak on their behalf.

    - Engagement: consulting with and providing information to lay people (stages 3 to 5 on Arnstein's ladder of participation[1]).

    - Involvement: directly involving individual lay people in our decision-making bodies (stages 6 and 7 on Arnstein's ladder).

7. Lay people can get involved in developing NICE guidance and standards. The development process generally follows these steps:

    - topic selection

    - scoping

    - committee recruitment

    - development

    - consultation

    - publication

    - updating.

Process for developing guidance and standards

8. The topics we develop guidance or standards on are selected and agreed with NHS England, the Department of Health and Public Health England. Topics are also referred directly to NICE by technology manufacturers or surgical practitioners.

9. We prepare a scope, which sets out what the guidance or standard will and will not cover. The scope also defines the priorities, outcomes and key questions that we will consider during development.

10. We ask an independent decision-making body (either a standing committee or a topic-specific committee) to consider the evidence identified by searches of the literature or submitted by a manufacturer, and use it to make recommendations on the topic.

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[1] Arnstein's ladder of participation describes a range of participation approaches, from a one-way transfer of information through to consultation and ultimately a co-produced shift in the balance of power between citizens and policy makers. Arnstein SR (1969) A ladder of citizen participation. Journal of the American Institute of Planners 35(4): 216–24.

11.   We hold a consultation on the draft recommendations, and invite stakeholders to comment. We amend the recommendations in line with stakeholder comments before we publish the final guidance or standard.

12.   We review and update guidance and standards regularly to ensure they reflect the latest evidence.

How lay people can get involved

13.   Individual lay people can get involved in developing NICE's guidance and quality standards in 4 main ways. They can become:

- a core member of a standing committee, working on a number of topics over a long period of time

- a topic expert member of a standing committee, working on a single topic for a short period of time

- a member of a topic-specific committee, working on a single topic over a long period of time

- an expert witness (also known as a patient expert), giving testimony on a single topic to 1 or 2 topic-specific meetings.

14.   With the exception of expert witnesses, all types of lay committee members are part of the decision-making processes, and have equal status to all other committee members. Further details about the different ways lay people can participate in NICE's decision-making bodies are in appendix B.

15.   NICE uses these forms of participation either on their own or in combination. For example, committees for clinical, public health and social care guidelines have topic-specific lay members, and committees for technology appraisals use a combination of core members and expert witnesses.

16.   We acknowledge that the variety of ways that lay people can participate in NICE's committees is confusing to our stakeholders and a potential barrier to engagement. However, we are not considering wholescale changes to these arrangements at present. We are instead seeking to standardise the approach as much as possible within the current limitations.

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What do we propose?

17. We have drafted the following evidence-based principles, and 7 proposals, to improve participation, engagement and involvement of lay people at NICE.

Principles

18. We propose to uphold the following principles for involving lay people in developing NICE guidance and quality standards:

- Topics chosen for guidance and standards are informed by the views of lay people[2], if possible.

- Key questions, outcomes and scopes for guidance and standards are informed by the views of lay people.

- Guidance committees take direct account of the perspectives of lay people, with minimum of 2 lay people on each committee.

- Guidance and standards take formal account of information[3] relating to people's experiences of care and services.

- Guidance and standards are written clearly and comprehensibly to inform people about the care available to them.

- Guidance and standards are disseminated and publicised to the public to raise awareness and support informed decision-making.

- Lay people are supported to work with us by the Public Involvement Programme, other NICE staff, committee members and chairs.

- Lay people have opportunities to:
  - get feedback from NICE on the effect and value of their contributions, and
  - give feedback to NICE about their experiences of participation, to help us improve the participation process.

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[2] Not all of NICE's programmes allow external people to contribute to selecting topics. If these opportunities exist, we will ensure the participation, engagement and involvement of lay people.
[3] By information, we mean information from a wide range of sources - such as formal published research, expert submissions and commentary, and individual testimony.

Proposals

19. We propose the following 7 changes to how we engage with and involve lay people in developing guidance and standards:

- standardise approaches
- involve people early
- incorporate information on people's experiences of care and services
- take new approaches to recruitment
- feed back to participants
- use social media
- make involving lay people everyone's business.

Standardise approaches

20. We propose standardising the approaches to participation, engagement and involvement of lay people across NICE's guidance and standards programmes.

21. This standardisation will:

- ensure the right input from the right people at the right time
- reduce unnecessary confusion and barriers, such as variations in terminology
- increase consistency and reduce inefficiency
- allow sharing of best practice across the programmes.

22. NICE has several diverse programmes that develop guidance and standards, using different processes and methodologies. Some programmes will need to continue to do things differently because of the legal status of their guidance.

What we will do

23. We will standardise processes for involving lay people across as many programmes as possible. This will include:

- standardising terminology across programmes
- taking more efficient approaches to identifying and recruiting lay people (see below)
- involving the same lay people throughout the development of a piece of guidance or standard
- building on areas of good practice within NICE.

Involve people early

24. We propose establishing earlier and continued direct involvement of lay people in the development of guidance and standards.

25. By involving people early in development, we can make sure that issues of concern and important outcomes are addressed and that relevant lay knowledge and experience can be used throughout.

What we will do

26. We will identify what process changes are needed to involve lay people earlier in development, particularly in the scoping process and, if possible, in the selection of topics. For some programmes, such as the technology appraisals, this will mean identifying expert witnesses at an earlier stage. For other programmes, such as guidelines and quality standards, topic expert or topic-specific lay committee members will need to be identified earlier.

27. We will also take a new approach to recruiting lay members to committees (see below). This will help us to identify relevant specialist lay people early, regardless of which programme their expertise is needed on.

Incorporate information on people's experiences of care and services

28. We propose being clearer about how we find and take account of information on people's experiences of care, and of their condition and its treatment. This information can be formal published research, expert submissions and commentary, and individual testimony.

29. We will also be more explicit about how we explain the way this information is incorporated into guidance and standards.

What we will do

30. In the short term, we will ask manufacturers of drugs, devices and other technologies that we are assessing to provide information on people's experiences of care and the condition when they submit information to the guidance development process. Guidance committees can consider this information alongside information from lay people. We will expect manufacturers to explicitly show the unmet need or other significant patient benefit that their technology addresses.

31. We will also establish a standardised way to routinely record and report how information and other relevant evidence from lay people is taken account of in the development of guidance and standards.

32. In the long term, we want development processes to include searching for and analysing evidence on people's experiences of care and services. These searches should also look for evidence on the particular issues that are most urgent and important to people living with a disease, condition or circumstance. We acknowledge that new approaches will be needed to analyse the information found by these types of searches.

Take new approaches to recruitment

33. We propose recruiting a broad pool of lay people with specific experience of a condition, service or type of care (specialist lay people). These people will be drawn on as needed to join guidance and standards committees as topic-specific or topic expert lay members, or act as expert witnesses.

34. Recruiting, training and supporting new specialist lay members for each new topic is no longer sustainable. We need to be more efficient in how we recruit specialist lay people. We will continue to recruit generalist lay people (core members) as needed.

What we will do

35. We will recruit a broad pool of specialist lay people with knowledge and experience relevant to topics coming up in the next 2 years. Topic expert lay members, topic-specific lay members and expert witnesses for guidance committees would then be drawn from this pool rather than recruited each time.

36. We will ensure that we maintain diversity in the backgrounds and experience of the lay people we work with and will try to maintain representation from a range of people with 'protected characteristics'[4].

37. This approach could enhance the skills and experience of the lay people who work with us, allowing them to gain in-depth experience across a wide range of NICE programmes. It could also reduce the burden of repeated recruitment activities.

38. To ensure we take account of a range of views, the pool would need to be refreshed on a regular basis. We will establish a wide network of interested lay people and organisations that we will draw on for expertise, and to act as a sounding board. This network will feed into the pool of specialist lay people.

39. We will continue to recruit core members of committees as needed. For some very specialist topics we will still need to recruit topic-specific or topic expert lay members rather than draw from the pool.

40. The technology appraisal and highly specialised technologies programmes use expert witness lay members (known as patient experts) for their standing committees. Patient experts are currently recruited only through nominations from specially invited patient organisations. We will expand this process to allow selection of patient experts from the pool of specialist lay people. If there is no suitable patient expert in the pool, people can be nominated by a relevant support organisation or can nominate themselves if they have suitable experience.

41. More details about the different types of lay members for guidance and standards committees and how they will be recruited are in table 1.

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[4] Under the 2010 Equality Act protected characteristics are: age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex; and sexual orientation.

Table 1 Proposed methods of recruitment by type of lay member

Type of lay member	Method of recruitment
Core member of a standing committee	Each vacancy advertised and recruited to individually
Topic expert member of a standing committee	Vacancies filled from the pool of specialist lay people in the first instance If no suitable candidate is available in the pool or the topic is very specialist, vacancies will be advertised and recruited to individually
Member of a topic-specific committee	Vacancies filled from the pool of specialist lay people in the first instance If no suitable candidate is available in the pool or the topic is very specialist, vacancies will be advertised and recruited to individually
Expert witness (patient expert) at a topic-specific committee	Vacancies filled from the pool of specialist lay people in the first instance Vacancies filled by candidates nominated by relevant stakeholder organisation or self-nomination If no suitable candidate is available in the pool or the topic is very specialist, vacancies will be advertised and recruited to individually

Feed back to participants

42.   We propose introducing a formal feedback mechanism so that lay people who help develop our guidance and standards are aware of the influence and impact of their contribution.

What we will do

43.   We will introduce a formal feedback mechanism giving people clear information about how we have taken their contribution into account. We will also continue to offer our lay participants the opportunity to tell us about their experiences of working with NICE, through exit surveys, so we can continuously identify areas for improvement.

Use social media

44.   We propose making better use of social media, alongside our existing communication channels, to tell lay people about our guidance and standards, and to enable them to communicate easily with us.

45.   We largely communicate with lay people through our website and our work directly with lay people and the organisations that represent them. Social media

is another useful communication channel, and a way to gather data on issues that concern people.

46. We have a Twitter account specifically to tell people about the activities of our Public Involvement Programme (@NICEGetInvolved). We also have a Twitter account (@NICEcomms) and a Facebook page that promote all NICE's products and initiatives.

47. Better communication with lay people through social media may mean they are more aware of our guidance and standards, and more likely to use them to inform their decisions about their treatment and care.

What we will do

48. We will develop a formal approach to using social media (such as Facebook, Twitter and patient group forums). We will use social media to:

- communicate messages about our guidance and standards

- communicate messages about opportunities to participate in NICE's work

- get feedback on particular projects or topics

- gather information about issues of concern.

Make involving lay people everyone's business

49. NICE staff members need to be aware of, and have a role in, engaging and involving lay people. Making the involvement of lay people a core activity for all staff will create an organisational culture that puts lay people at the heart of NICE's work.

50. We propose introducing new activities for NICE staff to reinforce the concept that involving lay people is everyone's responsibility.

What we will do

51. We will establish an internal oversight group made up of representatives from NICE teams. This group will provide support and insight to the Public Involvement Programme and reinforce the concept that involving lay people is a corporate activity.

52. We will develop a training session on NICE's approach to participation, involvement and engagement that will be included in induction for new staff. In addition, we will consider developing training for committee chairs and staff who have frequent interactions with lay people, such as coordinators and project managers.

53. We will promote the involvement of lay people in developing guidance and standards and ensure that their role is better integrated. To support this, we will publish regular news and blog posts about activities involving lay people on the NICE intranet and website.

These principles and proposals are broad and do not specify the detailed operational changes that will be needed for individual NICE programmes. The details will be included in future updates to programme-specific process and methodology manuals and will not be subject to further consultation.

These proposals assume that funding for activities to involve lay people at NICE will not increase. They also assume that governance arrangements for NICE's Citizens Council and its Meetings in Public will not change. These 2 programmes sit outside of the scope of NICE's Public Involvement Programme.

How can I share my views?

54. Please give us your views on our proposals for improving how lay people can participate in, engage with and get involved in the work of NICE.

55. Please provide your views separately for our proposals on:

- principles for involvement

- standardisation of approaches

- early involvement of lay people

- incorporating information on people's experiences of care and services

- new approaches to recruitment

- feeding back to participants

- using social media

- making involving lay people everyone's business at NICE.

56. The consultation will run from 1 December 2016 to 28 February 2017.

57. Please submit your comments to us via our online survey or to PPIConsultation@nice.org.uk using the form provided.

58. If it is not possible for you to return your comments electronically, then please send the comments form by post to:

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Appendix A: What do other people say about the best ways to involve lay people?

1.   We investigated various evidence sources to determine the best ways to involve lay people and to see how our current approaches compared.

2.   We conducted a review of the literature, a survey of the public and our stakeholders, a meeting with stakeholders from a variety of disciplines and interviews with NICE staff.

3.   Our evidence review raised the following points for us to consider when we were making proposals to improve NICE's approaches to involvement, engagement and participation of lay people. The evidence suggests that we should:

- Involve people as early as possible to ensure their contribution is effective.

- Involve a range of generalist and specialist lay people to ensure a balance of societal and vested interests.

- Invite lay people to help shape and prioritise the outcomes and key questions for guidance and quality standards.

- Consult on draft guidance and standards.

- Give lay members feedback on how their contributions were taken into account.

- Communicate widely the opportunities for lay people to be involved, and the impact and value of their involvement.

- Proactively identify evidence from lay people and incorporate it in committee discussions in a standardised way.

- Give lay people, staff and committee members better training on working collaboratively.

- Promote NICE and its involvement activities more widely.

- Make more effort to involve local lay people and organisations, and offer these groups a greater role in dissemination and implementation.

- Consider new approaches to recruiting lay members to committees (particularly topic-specific lay members and expert witnesses), to increase efficiency over the existing time-consuming process.

- Consider technology, especially social media, as a means of communication, both within and outside NICE.

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What does the literature say?

4.   Our review of the international literature on involving lay people identified the following main themes. A detailed description of the literature review and its findings is available in a journal article published in 'The Patient'[5].

5.   The literature showed that guidance and quality indicators continue to be an important way of improving healthcare around the world. Specifically, they improve the quality of care and experience that lay people receive. Ensuring representation of lay people in the development of guidance and quality indicators is therefore fundamental, both for reasons of democracy and improved quality.

6.   Although much progress has been made, further improvements are needed so that guidance development has meaningful input from lay people, through both their direct involvement and including information on their experiences.

7.   The literature review showed that evidence-based medicine has become more important over the years and involvement of lay people in health policy has increased. These 2 trends have influenced how lay people are involved in developing healthcare guidance around the world.

8.   However, evidence-based medicine relies on objective data, whereas involving lay people means using the subjective experiences of individual people. The tension between these 2 concepts creates complicated challenges for guidance developers, making it difficult to design processes that help lay people to get involved meaningfully and effectively.

9.   There is a strong body of evidence showing the value of involving lay people throughout the guidance development process, in particular during topic selection, developing the scope, forming recommendations and commenting on draft versions of guidance.

10.   The role of the chair of a guidance development group is particularly important for effective involvement of lay people. When electing new chairs, greater emphasis should be placed on their ability to facilitate supportive discussions.

11.   Including evidence on people's experiences would mean a broader range of perspectives is considered in guidance development, potentially increasing the relevance of the guidance. However, this approach would need a fundamental change to how evidence searches are conducted. In addition, this approach would need new methods of knowledge synthesis, input from social scientists and significant financial investment.

12.   Changing the format of guidance to highlight the relative uncertainty of recommendations, and to provide links to decision tools, is an important consideration for the future.

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[5] Rashid A, Thomas V, Shaw T et al. (2016) Patient and public involvement in the development of healthcare guidance: an overview of current methods and future challenges. The Patient [epub ahead of print]

13. Involvement of lay people can bring both individual and broader societal perspectives to the guidance development process. Some products, such as clinical guidelines on specific topics, may benefit more from involving patients or carers with experience of a particular condition. Other processes, such as standing committees for health technology assessments or indicators, may need lay members with societal perspectives.

14. Having lay people involved in decision-making bodies is critical, although other methods of involvement, such as engaging with people through social media, are also useful. Providing clearer instructions on how patient organisations can submit evidence to inform guidance development would make sure people in their networks can also participate.

15. Various instruments are available to evaluate the quality of guidance and the degree to which involving lay people has improved the quality. However, evaluating the impact of involving lay people in guidance development is difficult.

What do the public and our stakeholders say?

16. We ran a 2-week survey in January 2016 to explore how NICE can continue to involve lay people in a high quality, meaningful way. Participants were recruited in several ways, such as from the NICE website, email invitation, Twitter, and the staff newsletter and intranet.

17. Twelve questions (a mix of qualitative and quantitative) were posed to a targeted sample of people: external clinical and lay people; external organisations potentially involved in NICE work; NICE committee and board members; and NICE staff.

18. We also held a stakeholder engagement meeting to discuss the findings of the literature review and the survey.

What did the survey find?

19. We received 684 responses to our survey. A total of 553 of these responses were from people external to NICE. Overall 51 NICE staff responded, along with 80 members of the board and our advisory committees. Of the external respondents: 298 people identified themselves as patients, carers or members of the public; 81 were from our stakeholder organisations; and 128 were health and social care professionals. A total of 46 respondents identified themselves as public involvement experts.

20. When asked to prioritise the stages when lay people can be involved in guidance development, our respondents were largely aligned in terms of their priority areas (see table 2). The top 3 priorities were:

- defining outcomes and setting priorities
- setting key questions
- commenting on draft guidance.

Table 2 Top 3 stages of guidance development lay people should be involved in

All responses	External clinical and lay people and organisations	NICE committee members and board	NICE staff
Defining outcomes and setting priorities	Defining outcomes and setting priorities	Defining outcomes and setting priorities	Commenting on draft guidance
Setting key questions	Setting key questions	Sitting on NICE's committees	Defining outcomes and setting priorities
Commenting on draft guidance	Producing plain language versions of the guidance	Setting key questions	Setting key questions

21. People's views on who should be involved in our work were mixed. Respondents suggested that we needed a mixture of people with specialist topic knowledge and people with a more generalist 'citizen' view.

22. The following areas were identified as gaps in how NICE currently involves lay people:

- communication to raise awareness of:
  - how lay people can be involved in NICE's work
  - how their involvement affects NICE's work
  - the value of their involvement
- education and training for lay people, staff and committee chairs
- outreach engagement
- local engagement; for example, holding participation sessions for lay people in general practices and local engagement events
- implementation and dissemination of NICE guidance.

Comments from survey participants on how NICE could improve how it involves lay people

"Perhaps [do] more to raise awareness about how NICE operates, and how decisions are reached, and how guidelines are put together." − Lay committee member

"At the moment I think patient and public involvement is a well-kept secret. I only found out about it in a roundabout way, but I think that there are a lot of people who could be very useful and interested who don't know about the opportunities offered by NICE." − Patient

"Provide feedback on the impact of stakeholder involvement. Give examples of impact of patient and public involvement. Increase training committee chairs, committee members and NICE staff on the value of patient and public involvement." – Member of NICE staff

"There could be more training and recruitment type events. Often I see vacancies advertised, but I imagine only quite specific audiences apply. Maybe doing more outreach work to encourage more applications around minority areas, how to apply, what to expect etc. could be useful." − Lay committee member

"Patients and public should become more involved in guidance dissemination and should be able to try and influence commissioners to implement guidance." − Primary Care Project Officer.

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23.   In addition, it was suggested that we should consider other approaches to identifying information on people's experiences of care. These included:

- Providing people with a clearer and more structured approach to submit information on their experiences of care; for example, using:
  - focus groups, workshops, interviews and (online) surveys
  - online communities, panels and forums
  - social media; for example Facebook, Twitter and blogs.

- Providing appropriate support mechanisms; for example, signer, interpreter, written documents in multiple languages and physical assistance.

- Reviewing and incorporating evidence on people's experiences of care as well as academic evidence.

- Working in partnership with voluntary, community and social enterprise organisations to ensure we are making the best use of their data.

What did the stakeholder meeting find?

24.   We asked attendees at our stakeholder meeting to consider the results of the survey and how to prioritise which stages of guidance development lay people can be involved in. The participants acknowledged that it was difficult to prioritise 1 stage of involvement as more important than others. They reported

that every stage of guidance development that involved lay people felt important. As such, we should focus on how we can improve involvement rather than the less straightforward task of deprioritising stages for which involvement might be considered low value.

25. There was support among stakeholders for:

- Continuing to allow organisations and groups of people to submit evidence to be considered during development and respond to consultations on draft guidance. These submissions are highly valued – more so than submissions from individual people.

- Involving lay people earlier in the guidance development process to shape key questions and outcomes, and having both perspectives from a broad range of people and in-depth views from individual people.

- Having different types of lay people, such as specialist and generalist, contribute at all stages in the process. This helps to challenge the assumptions of others, and allows committees to consider different approaches for different conditions (for example, acute and chronic). However, any approach needs to be systematic.

- Actively searching for evidence on people's experiences.

- Making it clear that people will not always choose to have a new drug. People need information about the balance of benefits and harms and to make decisions for themselves.

- Continuing to do exit surveys for lay members of committees. Asking other members of committees for feedback was also mentioned, because they might spot additional value and impact that the lay members are not aware of.

- Learning from other organisations that do health technology assessments, and from other arm's length bodies.

- Considering new ways of using technology to gain a broader perspective from lay people; for example, using social media to aid hypothesis generation and to help inform questions or outcomes. People with specific conditions often communicate through charity forums – these could be a route to further engagement.

26. Some of the additional points raised by people at the stakeholder meeting included:

- Reconsidering the name of NICE's Public Involvement Programme to more accurately reflect the range of people we work with.

- Considering how we evaluate the impact of involving lay people, to ensure that their participation adds value.

- Providing clarity about whether our involvement focuses on patients and service users, or also incorporates views from the general public.

- Building capacity to support people who are not members of patient organisations, to gather more complete information.

- Considering our approaches to recruiting lay participants. We might need to stop doing some activities to refocus resources.

What do our staff say?

27. We conducted semi-structured interviews with all members of NICE's Public Involvement Programme and 2 non-executive directors.

28. The interviews largely concentrated on internal operating procedures, but they also identified a number of strategic issues. The responses will be used to inform how we change some of the internal ways of working within the Public Involvement Programme and across NICE's programmes.

29. The interviews identified that we need to:

- Ensure that involving lay people is considered to be the responsibility of everyone at NICE; for example, through induction and training.

- Set out clearer boundaries of responsibility between teams, to ensure all teams are aware which activities are the responsibility of the Public Involvement Programme and which are not.

- Demonstrate the value of the work done by the Public Involvement Programme, to our lay participants and others within and outside of NICE.

- Communicate clearly how people can get involved in what NICE does and use our recommendations, particularly using social media as a 2-way tool.

30. Many members of the team also expressed the desire to be as well thought of within NICE as we currently are outside of it, and to make sure that we remain ahead of the curve in terms of our approaches to involvement.

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Appendix B: Current ways lay people can participate in NICE's decision-making committees

Type of lay member	Role
Core member of a standing committee Sits on: • technology appraisal committees • highly specialised technologies evaluation committee • guidelines update committees • public health advisory committees • quality standards advisory committees • diagnostics advisory committee • interventional procedures advisory committee • medical technologies advisory committee • indicator advisory committee	Full member of a standing committee. Has a broad range of expertise and knowledge relating to patients, carers and the general public. Works alongside other core committee members from a range of health and care disciplines. Works on a wide range of topics. Helps to identify recommendations that should take account of people's preferences and choices. Part of the committee's decision-making and has voting rights. Does not represent the views of a particular organisation. Appointed to a single committee for a 3-year term in the first instance.
Topic expert member of a standing committee Sits on: • guidelines update committees • public health advisory committees • quality standards advisory committees • diagnostics advisory committee	Full member of some standing committees for a fixed period of time. Complement the core lay members on committees that have a combination of both core and specialist members (known as 'hybrid' standing committees). Normally recruited to work on a specific topic or technology. Has specialist knowledge of the individual topic or technology under discussion, either through personal experience or as part of a relevant organisation or support group. Part of the committee's decision-making and has voting rights. Does not represent the views of a particular organisation. Participates for 6 to 18 months, and for 2 to 10 meetings, depending on the work programme.

Member of a topic-specific committee	Full member of committees convened specifically to develop an individual guideline.
Sits on all committees run by: • the NICE internal guidelines team • the National Clinical Guidelines Centre • the National Guidelines Alliance • the NICE Collaborating Centre for Social Care	Has specialist knowledge of the individual topic, condition or area of care under discussion, usually through personal experience (as a patient, carer, family member or member of the public) or as part of a relevant organisation or support group. Takes part in decision-making and has voting rights. Does not represent the views of a particular organisation. Recruited for the duration of a guideline's development (normally about 2 years).
Expert witness at a standing committee	Invited attendee at 1 or more committee meetings.
Attends committees that routinely use expert witnesses (known as 'patient experts'): • technology appraisal committee • highly specialised technologies evaluation committee Attends committees that invite expert witnesses on occasion: • all guideline committees, including guideline updates committee • public health advisory committees • medical technologies advisory committee	Has specialist knowledge of the individual topic or technology under discussion, either through personal experience or as part of a relevant organisation or support group. Answers questions from members of the committee and gives testimony. Can submit written testimony to be shared with the committee. Expert testimony papers are posted on the NICE website with other sources of evidence when the guideline is published. Not a member of the committee: does not have voting rights and not involved in the final decisions or influence the wording of recommendations. Does not represent the views of a particular organisation. Nominated by patient organisations and selected by committee chair (some programmes allow for self-nomination).