NICE National Institute for Health and Care Excellence

NICE's approach to public involvement in guidance and standards: a practical guide

CONTENTS PAGE

NICE's approach to public involvement in guidance and standards: a practical guide

Background to this guide

1. This guide has been produced to explain how the National Institute for Health and Care Excellence (NICE) supports patients, service users, carers and members of the public who participate in its work. It describes the core activities of NICE's Public Involvement Programme (PIP). The guide provides an overview of the key principles that the PIP works to, along with more details of practical approaches to certain tasks.

Target audiences

2. This guide is for anyone interested in public involvement at NICE. Unlike many formal guides produced by NICE, this guide is primarily intended for external organisations and individuals already working with NICE and those who are interested in doing so in the future. It may of course also be of use and interest to the NICE teams that the PIP supports through its work.

Introduction

3. NICE provides national guidance and advice to improve health and social care. NICE is accountable to the Department of Health, but operationally it is independent of government. NICE's guidance and other recommendations are made by independent committees. The way NICE was established in legislation means that our guidance is only officially applicable to England. However, we have agreements to provide certain NICE products and services to Wales, Scotland and Northern Ireland.

4. Staff in the Public Involvement Programme (PIP) work across all of NICE's programmes but this guide aims to be general, and not specific to an individual programme. The PIP's 'how to' guides and factsheets[1] offer practical and detailed advice on how lay people can be involved in NICE's individual work programmes.

5. It should be noted that the information in this guide only covers the work of the PIP and not other NICE activities that include public and patient involvement such as committee meetings in public[2], and the work of the Citizens Council[3].

---

[1] www.nice.org.uk/about/nice-communities/public-involvement/develop-NICE-guidance
[2] www.nice.org.uk/Get-Involved/Meetings-in-Public
[3] www.nice.org.uk/get-involved/citizens-council

6. In addition, this guide focuses on the role of the PIP in supporting patients, service users, carers and the public in NICE's guidance and quality standards development activities. It does not cover other aspects of NICE's work in which the PIP has a role, such as the implementation of NICE guidance and quality standards, research and development or NICE's accreditation and evidence services.

Definitions

7. For the purposes of this guide the term 'lay member' is used to describe the patients, carers, service users, experts by experience, survivors, and members of the public who contribute to the development of NICE guidance and quality standards by sitting on a NICE committee. This includes people with a relevant care or support need, condition or disability, family and friends who provide unpaid care for them, people who work at voluntary and community sector organisations and people who have an advocacy role.

8. Individual work programmes within NICE use different terminology to describe the different types of committees, and the different types of lay committee members. For consistency, the terms adopted here are from Developing NICE Guidelines – The Manual[4].

9. NICE acknowledges that the term 'lay' is not one that is universally accepted or recognised, but this term has been adopted as the broadest term that covers the person's range of skills and experience. In addition, the term 'public involvement' is used throughout this guide to describe the involvement of patients, carers, service users, and members of the public in NICE's work.

10. Similarly, for the purposes of this guide, the term 'voluntary and community sector organisation' is used to describe the charities and other third sector stakeholder organisations representing the interests of, and speaking on behalf of, patients, carers, service users and members of the public.

Why NICE involves patients and the public

11. NICE is committed to patients, people who use health and care services, carers and the public having an active role in the development of its guidance and other products. The aim of public involvement in NICE's work is to ensure this unique perspective informs all our guidance products. As a result of this involvement, NICE guidance and standards have a greater focus and relevance for the people most directly affected by NICE recommendations.

---

[4] www.nice.org.uk/article/PMG20/chapter/1%20Introduction%20and%20overview

12. NICE's approach to public involvement is based on the principle that lay people, and organisations representing their interests, have opportunities to contribute to developing NICE guidance, advice and quality standards, and support their implementation.

13. The lay members of NICE's committees have equal status to the professional and practitioner members and their perspectives have equal value when considering the evidence. The views of all members of a NICE committee are given equal weight during discussions about the interpretation of the evidence and the lay members bring a unique perspective. The objective consideration of the evidence, combined with the diverse perspectives of the committee members, ensures that no one 'voice' is able to dominate when drawing up the recommendations.

14. Involving lay people is integral to NICE's approach to developing guidance, quality standards and other products. NICE's methods and processes for involving lay people are based on the best available evidence and on extensive practical experience. NICE has adopted a flexible model of involvement that allows us to develop different approaches for different programmes and areas of work. This flexibility allows for the most effective lay input.

Voluntary and community sector organisations

15. The PIP works with a wide range of voluntary and community sector organisations to build relationships, and encourage participation in NICE's work programmes. This includes outlining the ways by which they can get involved, and the potential benefits to their organisation and its membership that participation can bring. When NICE starts a new work programme, the PIP will particularly target organisations identified as benefiting most from being involved in that new area of work.

16. When NICE is asked to develop guidance or quality standards on a particular topic the Public Involvement Programme (PIP) identifies national voluntary and community sector organisations relevant to that topic and NICE invites them to register an interest. These may be both organisations with whom the PIP has had a long history and those that have not been involved with NICE before. Previous and potential stakeholder organisations are notified if NICE is planning to update an existing piece of guidance.

17. For some of NICE's programmes any national voluntary organisation or local Healthwatch can apply to register as a stakeholder[5] on the NICE website. For other programmes stakeholders need to be specifically invited to participate.

---

[5] www.nice.org.uk/get-involved/stakeholder-registration

There is more information about these different programmes on the PIP's [factsheet page](#)[6] on the NICE website.

18. The PIP works collaboratively with [Patients Involved in NICE](#) [7](PIN). PIN describes itself as:

"A coalition of over 80 patient organisations and is committed to enabling patient groups to engage productively with NICE. Independent from NICE and the pharmaceutical industry, they use their combined knowledge, experience and direct contact with patients from a wide range of conditions, to ensure NICE puts patients, carers, and patient groups at the centre of all of its work. They act as a critical friend and a respected and equal partner in developing and shaping aspects of NICE's work. They provide a forum for enabling patient groups to engage with NICE."

The Public Involvement Programme (PIP)

19. The Public Involvement Programme (PIP) is a team at NICE that develops and supports the organisation's public involvement activities. The PIP works across all of NICE's programmes to ensure that there are opportunities for lay people, and the organisations that support them, to participate meaningfully in NICE's activities, and that those opportunities are appropriately supported.

20. The PIP's work is supported and guided by NICE's Board-level [policy and principles](#)[8].

21. Specific PIP activities include:

- developing, implementing and reviewing methodologies to identify opportunities for lay involvement in NICE's work

- providing guidance and support on approaches to lay involvement for [NICE's Board](#)[9], its internal teams, and the external groups NICE commissions to develop its guidance

- working with voluntary and community sector organisations to support their involvement in specific guidance or quality standard topics

- providing information, training and support to individual lay people who contribute directly to NICE's work

- offering advice to guidance developers on issues relevant to the scoping and development of NICE guidance

---

[6] www.nice.org.uk/about/nice-communities/public-involvement/develop-NICE-guidance
[7] www.nice.org.uk/about/nice-communities/public-involvement/pin
[8] www.nice.org.uk/about/nice-communities/public-involvement/patient-and-public-involvement-policy
[9] www.nice.org.uk/about/who-we-are/board

- contributing to the development of the lay versions of NICE guidance

- evaluating lay involvement in NICE activities.

22. This guide focuses on PIP support for public involvement in guidance and standards development but the PIP's activities are wider than this; there is more information about the PIP's additional activities on the NICE website[10].

Core stages of guidance and quality standards development

23. The production of all NICE guidance and quality standards follows the same fundamental stages of development from referral through to support for implementation. These stages are outlined in figure 1.

Figure 1: core stages of guidance development[11]
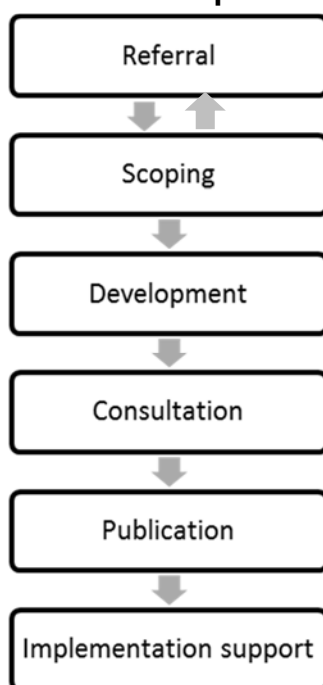
Referral and notification of topics

24. The topics on which NICE develops guidance and quality standards on come from a number of sources, and can be referred or notified to NICE depending on the relevant programme. There is more information about the various referral and notification approaches[12] on the NICE website and in the paragraphs below.

---

[10] www.nice.org.uk/about/nice-communities/public-involvement

[11] Please note that for some programmes the scoping and referral sequences are reversed, as indicated by double-arrow.

[12] www.nice.org.uk/about/what-we-do/our-programmes/topic-selection

Referral

25. For most work programmes, NICE can only develop guidance and quality standards on topics that are part of a formal referral. Two organisations can refer topics to NICE on the direction of government ministers – NHS England and the Department of Health. The latter can include a joint referral from the Department of Health and another government department such as the Department for Education.

26. On occasion, consultations are held on potential topics for NICE's guidance and quality standards. Views are sought from stakeholders on the suitability of these topics for NICE's work programme. The Public Involvement Programme (PIP) works with voluntary and community sector organisations to encourage them to take part in these consultations, and thus to help shape NICE's work programme.

Notification

27. For some of NICE's programmes topics can be notified directly to us by clinicians or companies rather than having to be formally referred. Notification to NICE of new procedures or technologies usually comes from clinicians involved in the development of new surgical techniques or from companies who develop or distribute new medical technologies. Members of the public, or voluntary and community sector organisations can also notify us of topics. If a member of the public or a voluntary and community sector organisation wishes to make a notification, the PIP can support them to complete their notification form.

The scoping phase

Scoping meeting or workshop

28. Most programmes at NICE run a workshop or meeting with stakeholder organisations at the start of the process of developing their guidance. At these meetings the stakeholder community helps NICE's guidance developers finalise the scope document. The scope defines the question(s) to be addressed in the guidance and therefore and shapes all future work on the topic.

29. Where a NICE programme is running a scoping meeting or workshop that needs input from voluntary and community sector stakeholders, the Public Involvement Programme (PIP) will contact them to encourage them to attend the meeting and to offer support. Where voluntary and community sector organisations attend the meeting, someone from the PIP will also attend to 'meet and greet' them, and in some cases, to give a formal presentation on the role of lay people and organisations in NICE's guidance development process.

Scope consultation

30. The scoping workshop is usually complemented by a written draft scope consultation. The PIP encourages relevant voluntary and community sector stakeholder organisations to submit comments on the scope. The PIP advises voluntary and community sector stakeholders to attend the meeting, if possible, as well as to submit comments by email during the consultation.

31. There is more information about the different mechanisms for engagement at the scoping stage in the 'how to guides' and factsheets[13] on the NICE website.

Recruitment and identification - finding NICE's lay members and experts

Overall principles

32. Two of NICE's commitments to lay involvement, as specified in the patient and public involvement policy[14] are to:

    - ensure that all NICE Committees and working groups[15] have at least 2 lay members (e.g. patients, those who use services, carers, advocates, members of the public)

    - provide opportunities for patients, service users, carers and the public to give evidence and testimony that can inform the development of NICE guidance, advice, standards, and other products

33. All NICE's guidance and standards committees have at least 2 lay members with either direct experience of the condition, services or topic being covered by the guidance or standards, or with general lay experience that they can bring to bear on a range of topics. This helps to ensure that the guidance is relevant to people affected by the recommendations and acknowledges general or specific preferences and choice.

34. Lay members' expertise may be drawn from their experiences as a patient, service user, carer or family member, or as a member or an officer of a voluntary or community sector stakeholder organisation or support group. However, as for all members of NICE committees, they are not expected to represent the views of any particular organisation.

35. The PIP supports and facilitates the recruitment and identification of all lay members of NICE's guidance and standards development committees.

---

[13] www.nice.org.uk/about/nice-communities/public-involvement/develop-NICE-guidance
[14] www.nice.org.uk/about/nice-communities/public-involvement/patient-and-public-involvement-policy
[15] Hereafter known as 'committees'

36. All lay people recruited to work with NICE in an individual capacity are allocated a named member of the PIP who supports them throughout their tenure.

About lay contributors and how they are identified

37. There are 4 primary ways in which individual lay people can participate in NICE's guidance and quality standards development. They can become:

- a core member of a standing committee.

- a topic expert member of a standing committee.

- a member of a topic-specific committee, such as a guideline committee.

- an expert witness.

38. For some topics, there may be the opportunity to participate in a group discussion, interview or survey to help the committee answer specific questions or give feedback on draft recommendations.

39. Additional members with specialist knowledge may be co-opted to a committee for 1 or more meetings to provide expert input. Unlike expert witnesses, co-opted members contribute to the development of recommendations. However, unlike the other standing members, they do not have voting rights and do not count towards the quorum.

40. The lay members and witnesses are recruited or identified in 3 different ways, as set out in table 1, all of which are administered and supported by the PIP:

- Open advertising and recruitment.

- Targeted identification through expressions of interest.

- Nomination: self-nomination, nomination by Committee members or via voluntary and community sector organisations.

Table 1: recruitment and identification of lay contributors

		Type of recruitment or identification		
		Open recruitment	*Expression of interest*	*Nominations*
Type of lay contributor	*Core standing*	Yes	No	No
	Topic expert	Yes	Yes	No
	Topic specific	Yes	No	No
	Expert witness	No	No	Yes

41. The approximate length of commitment for each type of contribution is indicated in table 2.

Table 2: length of commitment for lay contributors

		Length of commitment	*Number of meetings*
Type of lay contributor	*Core standing*	3 years in the first instance	Approximately 1 meeting per month
	Topic expert	6-18 months	Between 2 and 10 meetings
	Topic specific	14-24 months	12-14 meetings
	Expert witness	1 meeting	1 meeting

Open advertising and recruitment

Advertising

42. NICE recruits the majority of lay committee members using an open advert on the join a committee[16] page of the NICE website. Anyone with an interest can apply for one of these positions.

43. To support this process, the PIP drafts and uploads the following documentation:

- The content of the advert as it appears on the website.

- A tailored role description and person specification. This is similar to recruitment paperwork for an employment application; it details things such as the skills and experience needed for the role, the commitment needed, the support on offer and information about payment.

- An application form to ensure applicants supply standardised categories of information (it is for this reason that CVs are not accepted).

- Support information, including details of who to contact should the applicant have questions about the post.

44. Roles are usually advertised on the NICE website for 4 weeks. The PIP notifies relevant networks and organisations about the vacancy and encourages them to disseminate the opportunity among its members. The PIP notifies any individuals who have expressed an interest in either the topic or committee type.

45. Applications for lay member vacancies are sent to the PIP. Applicants for lay vacancies are asked to complete and return a declaration of interests form and an equalities monitoring form, along with their application form.

---

[16] www.nice.org.uk/get-involved/join-a-committee

Processing applications

46. When applications are received they are processed by the PIP. This includes logging each application received and separating the anonymous equality monitoring data from the applications. All equality monitoring data of lay members is recorded then analysed on an annual basis to feed into NICE's annual Equality Report.

47. Once processed, the PIP sends all applications to the recruiting team which makes its decisions using the formal criteria in the role description and person specification, and in accordance with NICE's corporate committee recruitment policies[17]. On request, the PIP will advise the recruiting team on aspects of the selection process.

48. On occasion the PIP may short-list or long-list the applications against the criteria in the person specification. This is the exception rather than the rule and may happen when there are a large number of applications for a particular vacancy or where the topic under consideration is particularly sensitive.

Following recruitment

49. Once the successful applicants have been notified and have accepted their place on the committee, the recruiting team notifies the PIP. The PIP then initiates its programme of ongoing support (paragraph 61-68 onwards).

Targeted identification through expressions of interest (topic expert members)

50. Where a NICE committee is considering a very narrow topic area in which NICE has already developed guidance, there may not be an open advertisement for topic expert members.

51. In these circumstances lay people who have previously worked with NICE on a relevant topic are invited to submit an expression of interest to be considered for topic expert membership of the committee. The recruiting team then selects applicants with the most relevant experience from these expressions of interest.

52. The PIP does not directly seek these expressions of interest but is informed by the recruiting team of the successful lay topic expert member. At this point the PIP initiates its programme of ongoing support.

---

[17] www.nice.org.uk/Media/Default/About/Who-we-are/Policies-and-procedures/Committee-recruitment.pdf

53. If no expressions of interest are received, or no applicant is suitable, the recruiting team will then approach the PIP to move to further advertise the role. In these circumstances paragraphs 42-49 will apply.

Nomination for expert witnesses - via voluntary and community sector organisations, Committee members, or self-nomination

54. Expert witnesses are invited to give testimony to committees in some of NICE's programmes. Experts may be drawn from a wide range of areas as appropriate, including government and policy, research, practice, individual patients, people using services, carers, or the community and voluntary sector.

55. Expert witnesses attending a committee meeting are invited to answer questions from members of the committee. They may be invited to present their evidence at a committee meeting in the form of expert testimony based on a written paper. The written paper may be shared with the committee before the meeting or the paper may be submitted by the expert after the meeting. Any written expert testimony papers are posted on the NICE website with other sources of evidence at publication.

56. Expert witnesses are not members of the committee; they do not have voting rights, and are not be involved in the final decisions about recommendations and quality statements.

57. Depending on the NICE programme expert witnesses may self-nominate or be nominated by committee members. For other NICE programmes such as technology appraisals, selected stakeholder organisations are invited to nominate expert witnesses. The PIP aims to support the voluntary and community sector organisations in understanding the importance of lay experience as part of expert witness testimony, and encourages diverse and appropriate nominations.

58. The choice of which of the nominee to invite to be an expert witness is usually the responsibility of the relevant committee chair. Once the lay expert witnesses have been selected, the PIP will offer them support:

- by telephone before the meeting at which they will be giving testimony
- face to face at the Committee meeting
- by email after the Committee meeting.

59. In addition to this personalised support, the PIP has developed [factsheets](#)[18] that provide further general, detailed information about the role of the expert witness and the support available from the PIP.

Resources and support for public involvement

Informal support and advice during guidance and standards development

60. The Public Involvement Programme (PIP) offers informal support and advice to lay members, expert witnesses and voluntary and community sector organisations throughout their time working with NICE.

For lay Committee members

61. Once the PIP gets notification of the appointed lay members from the recruiting team, the PIP staff member assigned to that work programme or topic emails the new lay member. The purpose of the email is to:

- introduce PIP

- explain the role of the PIP in providing advice and support

- provide brief information about the next stages in their committee process and what to expect

- to offer a phone call to provide an opportunity to ask any questions and help develop a relationship between the PIP and the lay member.

62. The PIP provides tips and other additional written information to new lay members to help them work effectively on the committee.

63. The PIP attends the lay member's first committee meeting to welcome them in person and introduce them to other members of NICE staff and the committee. In some cases the team running the committee provides this welcome. PIP may offer a face-to-face meeting before the first meeting to talk through information provided in the information pack and answer any questions that the lay member may have.

64. PIP contacts new lay members again following their first committee meeting. This provides them with an opportunity to discuss their initial thoughts and observations. As starting work on a committee can be quite an overwhelming or intense experience, the second contact provides the PIP with the opportunity to provide support and reassurance.

---

[18] www.nice.org.uk/about/nice-communities/public-involvement/develop-NICE-guidance

65. Once lay members are established on their committees, PIP provides support on an ad hoc basis by contacting them by email periodically, attending a committee meeting, and responding to any contact made. Contact is initiated primarily by the lay member and the frequency and nature of the contact will vary between lay members.

66. At the end of a lay member's time working with NICE (which can vary from attending 2 or 3 meetings for topic expert members, to several years as a core member), PIP contacts them by email to thank them for their contribution and offer them the opportunity to reflect on their time on the committee or discuss any feedback they may have. The PIP draws their attention to the exit survey described in paragraph 106.

67. Some lay members need additional support. This may be because they have a particular health condition that might make working on a committee more challenging, have a learning or physical disability, or a mental health condition. In these situations PIP works with them to establish what their support needs are and how both PIP and the guidance and standards developers can work to meet those needs. Examples of support provided by PIP could include more frequent telephone contact, or a PIP staff member attending a committee meeting with a lay member if they are having a particularly difficult time.

68. This support is additional to the reasonable adjustments that NICE makes to meet the needs of disabled committee members. It differs from more formal support that a lay member may need, such as having a carer or support worker attend a meeting with them, which is outside the scope of this guide. Specific information about how PIP works with children and young people, and other people with specific support needs, is discussed in paragraphs 92-95, and further information on formal training offered is in paragraphs 83-88.

For lay expert witnesses

69. PIP may have contact with potential expert witnesses prior to them being formally invited to take part in a meeting. This may include encouraging the person to nominate themselves or other witnesses for a topic, or advising them how to complete the necessary forms in order to take part in a meeting.

70. When PIP is notified that an expert witness has been invited to take part in a NICE committee meeting, PIP emails them. As with lay members, the purpose of the email is to:

- introduce the PIP

- explain the role of the PIP in providing advice and support

- provide brief information about the next stages in their committee process

- outline what to expect and any actions to take such as completing forms or statements

- and finally to offer a phone call to provide them with the opportunity to ask any questions and help develop a relationship between the PIP and the expert witness.

71. PIP emails supporting documents such as hints and tips documents to the expert witness for them to refer to throughout their involvement with NICE.

72. The PIP attends the relevant committee meeting to welcome the expert witness, introduce them to key committee members and the NICE team, and ensure that they are comfortable and ready to participate in the meeting.

73. The PIP stays in the meeting while the expert witness is present and may take notes on any lay issues raised during the deliberations and provide these notes to the NICE technical team involved in the meeting.

74. Following the meeting PIP contacts the expert witness to thank them for their participation and inviting any feedback on their experience.

75. If the expert witness is invited to subsequent meetings PIP will again contact them prior to the meeting and provide support as needed.

For voluntary and community sector stakeholder organisations

76. The PIP has contact with voluntary and community sector organisations at key points in the development of NICE guidance, standards and other products. PIP provides support by encouraging voluntary and community sector organisations to participate in the development of the guidance and quality standards, and its implementation, explaining the different stages of the guidance and quality standards development processes and guiding voluntary and community sector organisations through the paperwork they may need to complete to take part.

77. PIP provides email and telephone support to organisations engaging with NICE's processes to support their participation. In most cases this support is initiated by contact from the voluntary and community sector organisation, but the PIP may contact organisations to explain more about NICE and how to engage with NICE processes, especially if the organisation is new to working with NICE.

78. PIP can arrange face-to-face meetings with voluntary and community sector organisations to discuss specific work programmes, upcoming topics of interest, and for the PIP to gain a greater understanding of the interests of the organisation and any challenges they face in engaging with NICE. Face-to-face meetings help to further develop the relationship between the organisation and NICE.

Resources to support involvement during guidance and standards development

For lay members and lay expert witnesses

79. The Public Involvement Programme (PIP) has developed a range of resources to support the involvement of lay members on NICE committees. This written information includes:

    - further information about the NICE programme with which they will be working

    - support and advice about making a valuable contribution to the work of the committee

    - a glossary of key terms

    - a list of useful websites.

80. Once invited to participate in a NICE committee meeting, expert witnesses are sent information prepared by the PIP to support them during their time working with NICE. This includes further information about the process in which they will be involved; how the meeting will be run; and how to make an effective contribution to the meeting.

81. Resources are tailored to each work programme and reviewed regularly.

For voluntary and community sector organisations

82. The PIP has produced a range of resources[19] to support the involvement of voluntary and community sector organisations in NICE's work. These include factsheets for different NICE work programmes explaining how the guidance is developed, opportunities to get involved, advice about the best ways of engaging with NICE, and the support available to people who do get involved. The PIP has developed resources to support and promote the implementation of several NICE guidance products.

Training offered by PIP

For lay members

83. The Public Involvement Programme (PIP) runs training sessions and workshops for lay members who sit on NICE committees. This includes induction training sessions for lay members who are at the beginning of their work and workshops for those who have been involved for some time.

---

[19] www.nice.org.uk/about/nice-communities/public-involvement/develop-NICE-guidance

84. All newly recruited topic specific lay members are invited to a PIP training day and encouraged to attend. The main purpose of the day is to explore how guidance is developed and the role of lay members, to help participants contribute effectively on their group or committee.

85. The PIP runs follow-up workshops for lay members focusing on the end stages of guidance development and beyond to publication and promotion.

86. The PIP invites technical experts from NICE and its collaborating centres to contribute, alongside former lay members who share their experiences as guidance developers.

87. The PIP organises workshops for standing lay members. These workshops provide an opportunity for shared learning within and across NICE's standing committees.

For voluntary and community sector organisations

88. The PIP runs workshops for voluntary and community sector organisations who work with NICE, or who are interested in doing so. These are interactive sessions, termed 'masterclasses', and are free of charge to the participating organisations. Topics are chosen to reflect demand, and have included: Introduction to NICE; Social Care at NICE; Implementation; What's New in Technology Appraisals; Health Economics for Lay People; and Use of Evidence at NICE. Further information is on the masterclasses webpage[20].

Payment

89. NICE offers payment (known as honoraria) to individual lay people whose input at a meeting has been specifically requested, such as membership of a NICE committee. Payment is offered for face-to-face meetings of any duration or for a teleconference where that input is scheduled to last more than 2 hours. This payment is offered irrespective of whether the person is a paid employee of an organisation. The payment is offered to the individual directly, although the payment may be declined.

90. The payment is offered where individual lay expertise is sought. Where a lay organisation's view is sought, payment is not offered.

91. There is more information about the payment policy and some frequently asked questions available on the NICE website[21].

---

[20] www.nice.org.uk/About/NICE-communities/Public-involvement/Masterclasses
[21] www.nice.org.uk/about/nice-communities/public-involvement/patient-and-public-involvement-policy

Involving children, young people and adults, including those with specific needs

92. NICE acknowledges that the mechanisms for involvement described above do not necessarily allow for all voices to be heard. For some topics, these mechanisms need adaptation or supplementation to involve specific groups affected by the guidance such as children and young people, and people of all ages with learning disabilities or cognitive impairment. These adaptions could involve a change to the way a meeting is run, or additional work such as having a parallel reference group of service users, running focus groups, or conducting a survey or interviews.

93. NICE has principles for working with children and young people which are set out in the [patient and public involvement policy](#)[22]. As part of the work putting these principles into practice, NICE is embedding a systematic approach to ensuring the views of children and young people are included in guidance development.

94. NICE is developing its approach to involving people with learning disabilities and this is reflected in [Developing NICE guidelines – the manual](#)[23] which includes the following instruction: "For all guidelines covering children and young people and those focusing on people with a learning disability or cognitive impairment, the Developer should consider how to involve people affected by the guideline when they begin work on the topic, and should reflect this in its plans."

95. There is a [summary](#)[24] of the range of different ways in which such groups can be involved in developing NICE guidance on the NICE website. This includes details of the advice and support available from the PIP.

During the consultation phase

Support for participation and consultation

96. All draft guidance and quality standards are posted on the NICE website for a period of consultation and stakeholder organisations are invited to comment. This is a stakeholder's only opportunity to comment on the content and wording of the guidance and quality statements. The Public Involvement Programme (PIP) usually encourages voluntary and community sector stakeholders to comment to ensure that the views of patients, service users and carers are included.

97. NICE will tell all stakeholder organisations well in advance about the consultation dates for each guidance or quality standard for which they are registered. At the

---

[22] www.nice.org.uk/about/nice-communities/public-involvement/patient-and-public-involvement-policy
[23] www.nice.org.uk/article/PMG20/chapter/1%20Introduction%20and%20overview
[24] www.nice.org.uk/article/pmg21/chapter/appendix-b-involving-people-affected-by-the-guideline-children-young-people-and-adults

start of consultation all stakeholder organisations are informed and sent the links to the draft guidance or quality standard, and information about the deadline for comments.

98. Although individuals are able to comment, they are encouraged to submit their comments via a relevant voluntary and community sector stakeholder organisation.

99. The PIP encourages relevant voluntary and community sector stakeholder organisations to submit comments on the draft guidance. The PIP can support voluntary and community sector organisations with any questions about consultations, or about commenting on the draft guidance or quality standard. Further information can be found in the PIP [factsheets](#)[25].

100. All comments received will be collated and considered by the relevant NICE centre, directorate or collaborating centre. Responses to the comments received on draft guidance will be published alongside the final guidance. Comments received from individuals, or comments received on draft quality standards, will be considered by the Committee but will not receive a formal response.

Publication

101. All stakeholder organisations will be notified when the guidance or quality standard is published.

102. For some of NICE's programmes an advance copy of the guidance is made available to stakeholders before publication. This is confidential until the guidance is published. This allows stakeholders to check for factual errors, but it is not an opportunity to comment further on the guidance. This pre-publication check can be particularly helpful for voluntary and community sector stakeholder organisations as it allows them to prepare their staff and volunteers for any queries they might get in relation to the guidance or quality standard from their members or users of their helpline services.

After the guidance or quality standard is published

Inclusion of support organisations in the Information for the Public (IFP)

103. For most guidance types and quality standards, NICE publishes a plain English version called Information for the Public (IFP). Lay members are involved in developing many of these IFPs. The IFPs for most guidance types include a list

---

[25] www.nice.org.uk/about/nice-communities/public-involvement/develop-NICE-guidance

of support organisations, identified by the Public Involvement Programme (PIP), with their helplines and websites for further information, advice and support.

Targeting of supporting organisations for quality standards

104. NICE invites stakeholder organisations to express interest in formally supporting each quality standard it publishes. The PIP helps identify key voluntary and community sector organisations to encourage them to express an interest. Supporting organisations agree to undertake specific tasks or activities to promote the use of[26] the quality standard.

Promotion of implementation support activities

105. The PIP encourages lay members and voluntary and community sector organisations, including local Healthwatch, to promote NICE guidance and help support getting it put into practice. For example, prior to publication, the PIP contacts key stakeholder organisations for each NICE guideline with suggestions of action they might take and contact details for the NICE Implementation Adviser. The PIP encourages lay members and voluntary and community sector organisations to share what they are doing to support implementation of NICE guidance, so that others can learn from them.

Exit surveys

106. The PIP uses an online exit survey to enable lay people who have worked with NICE to provide feedback on their experiences. The survey has been designed in collaboration with lay members to ensure it is user friendly, straightforward and accessible. The survey is tailored to lay members depending on what type of committee member they have worked as and can be responded to anonymously or not at their discretion.

107. The survey is emailed to the lay member once their role at NICE has ended. The survey has a mixture of questions, including ratings on a scale and open questions.

108. Results of the survey provide the PIP with opportunities to learn lessons and change or adjust things that are not working. Feedback from lay members is used to develop and improve the support the PIP provides, and to improve lay members' wider experience of working with NICE, with suggested new initiatives and areas for improvement implemented as appropriate.

109. Survey results are collected and analysed on a quarterly basis, and the findings are discussed at the PIP team meetings to identify recommendations for improvement. The PIP works with internal teams across NICE, along with relevant external stakeholders, to make improvements. A report is produced

---

[26] www.nice.org.uk/Standards-and-Indicators/Developing-NICE-quality-standards

every 12 months for the senior management team and NICE Board as part of the PIP's Annual Report.

110. The exit survey itself is reviewed every 6 months to ensure it remains accessible and fit for purpose.

Further information

111. The PIP has produced a number of [factsheets and other helpful documents](#)[27] that describe in more detail how individuals and organisations can participate in the development of NICE guidance and quality standards.

112. [More information](#) about the PIP is available on the NICE website. The team can be contacted by emailing [pip@nice.org.uk, calling +44 (0)300 323 0140,](#) or writing to Public Involvement Programme, National Institute for Health and Care Excellence, Level 1A, City Tower, Piccadilly Plaza, Manchester, M1 4BT

---

[27] [www.nice.org.uk/about/nice-communities/public-involvement/develop-NICE-guidance](#)

Glossary

Collaborating Centre
NICE contracts five Collaborating Centres for the production of its clinical and social care guidelines. They are partnerships between Royal Colleges, academic institutions, NHS trusts and other organisations.

Core member
A standing Committee usually has between 6 and 12 core members. They serve for an initial period of up to 3 years and work on all guidance developed by the Committee during that period. The core members of a standing Committee include at least 1 practitioner and 1 lay member, and may include an economist.

Expert witness
An expert invited to attend a Committee meeting to provide evidence from their experience and specific expertise. Expert witnesses answer questions from Committee members and may be invited to present evidence in the form of expert testimony, which is published on the NICE website when the guidance is published. Expert witnesses are not members of the Committee. They have expert knowledge of 1 or more of the following areas: experience and views of practitioners; people using services; carers or the community and voluntary sector; government and policy; or research and practice.

Guideline Committee
A type of topic-specific committee put together for a single guideline topic. A NICE committee is the advisory group that considers the evidence and develops the recommendations, taking into account the views of stakeholders. Members include practitioners and professionals (both specialists and generalists, and/or academics), care providers and commissioners, people using health and care services and/or their family members, carers or advocates, or people from communities affected by the guideline.

Guidance
Recommendations produced by NICE. All guidance is developed by independent Committees and is consulted on. There are 6 types of guidance:
- guidelines covering clinical topics, medicines practice, safe staffing, public health and social care
- interventional procedures guidance
- technology appraisals guidance
- highly specialised technologies guidance
- medical technologies guidance
- diagnostics guidance.

Information for the Public (IFP)
A summary of the key messages of the guidance in everyday language, written for users of health and care services, carers and the public. It follows the principles of the [Information Standard](#)[28].

Lay member/lay person
A Committee member, or other contributor to NICE's work, who has personal experience of using health or care services, or who is from a community affected by the guidance. A lay member can also be someone with experience as a carer, an advocate, or a member or officer of a voluntary or community organisation.

Patients Involved in NICE (PIN)
A coalition of over 80 patient organisations and is committed to enabling patient groups to engage productively with NICE. Independent from NICE and the pharmaceutical industry, they use their combined knowledge, experience and direct contact with patients from a wide range of conditions, to ensure NICE puts patients, carers, and patient groups at the centre of all of its work. They act as a critical friend and a respected and equal partner in developing and shaping aspects of NICE's work. They provide a forum for enabling patient groups to engage with NICE, working alongside NICE's Public Involvement Programme.

Public Involvement Programme (PIP)
A team at NICE that develops and supports patient, carer and public involvement.

Quality standards
NICE quality standards are concise sets of prioritised statements designed to drive measurable quality improvements within a particular area of health or care. They are derived from the best available evidence such as NICE guidance and other evidence sources accredited by NICE. They are developed independently by NICE, in collaboration with health and social care professionals, their partners and service users.

Recruiting team
The team with whom the decisions rest about who to recruit to a committee. Normally this consists of the Chair of the committee, the NICE Centre Director or Collaborating Centre Director, and a senior member of the relevant NICE programme team.

Stakeholders
Stakeholders are organisations with an interest in a particular guidance topic; they may represent people whose practice or care is directly affected by the guidance. They can include: national organisations for people who use health and social care services, their families and carers, and the public; local Healthwatch organisations; national organisations that represent health and social care practitioners and other people whose practice may be affected by the guidance, or who can influence uptake of the guidance recommendations; public sector providers and

---

[28] www.england.nhs.uk/tis/

commissioners of care or services; private, voluntary sector and other independent providers of care or services; companies that manufacture drugs, devices, equipment or adaptations, and commercial industries relevant to public health; organisations that fund or carry out research; government departments and national statutory agencies. Stakeholders are encouraged get involved at all stages.

Standing committee

A Committee which works on multiple guidance topics. It may comprise only core members or a combination of core and topic expert members.

Topic expert member

Experts on a guidance topic who join a standing Committee to work on that single topic. They may include lay members, practitioners, providers and commissioners.

Topic specific member

A Committee member appointed to a topic-specific group, convened for the development of one specific guideline. They may include lay members, practitioners, providers and commissioners.

Voluntary and community sector

Charities and other not for profit organisations, often speaking on behalf of patients, people who use services and carers. Also known as the third sector.