

Contributing to public health guidance – a guide for the public

Factsheet 2: How organisations representing public interests can get involved – becoming a stakeholder

This factsheet is one of a series that describes how individuals and organisations can help NICE develop public health guidance.

- Factsheet 1: How NICE develops public health guidance
- **Factsheet 2: How organisations representing public interests can get involved**
- Factsheet 3: How individuals can get involved
- Factsheet 4: Support for community members involved in developing guidance
- Factsheet 5: Helping to put NICE recommendations into practice

The series aims to:

- help community members and organisations representing public interests take part in developing NICE public health guidance
- explain why NICE wants them to be involved
- explain what community members and organisations can expect if they do get involved
- explain how NICE supports individuals and organisations throughout the development of guidance.

What is NICE?

The National Institute for Health and Care Excellence (NICE) is an independent organisation that helps those working in the NHS, local authorities and the wider community deliver high-quality health and social care. We provide the following types of guidance or advice:

- Clinical guidelines – recommendations for the NHS about the treatment and care of people with specific conditions
- Health technology guidance – recommendations for the NHS on new and existing medicines, diagnostic techniques, treatments and procedures
- Public health guidance – recommendations for local authorities, the NHS and others on promoting and maintaining good health and preventing disease
- Social care guidance – recommendations for local authorities and service providers about care for people using social care services

Different types of guidance apply to different parts of the UK. NICE also has other related responsibilities, such as developing quality standards for the NHS, local authorities and other providers of health and social care services in England. In all our work, we aim to ensure that our methods and guidance promote equality. For more information about our work see www.nice.org.uk

What do we mean by ‘community members’?

We use the term ‘community members’ in this series to cover all groups of people who contribute to NICE public health guidance from a public or community perspective. This includes people with direct experience of public health activities (such as people who have used a service to help them quit smoking) and their carers, as well as individuals involved in health-related voluntary and community action (paid or unpaid).

How organisations representing public interests can contribute – registering as a stakeholder

What is a stakeholder?

A stakeholder is an organisation that has registered its interest in NICE guidance that is being developed. Stakeholders are sent the drafts of the scope and the guidance and are asked for comments.

Being a stakeholder does not commit your organisation to anything. It does not affect your organisation's independence or mean that your organisation has to endorse the final guidance. Registering as a stakeholder simply ensures that you are kept informed about the guidance as it is developed (see Factsheet 1). As a stakeholder, you will automatically be invited to contribute at key stages but there is no obligation to do so.

Commercial or NHS organisations, government departments, local authorities and other statutory bodies can register as stakeholders. So can national organisations representing professional groups and public, patient or service user, carer or community interests. Occasionally, regional or local groups may be stakeholders, if there is no national organisation to represent a particular group of people. Local Healthwatch are also eligible to register as stakeholders for topics they are interested in.

How to register as a stakeholder

When the Department of Health gives NICE new topics for public health guidance, we contact all the organisations that have been stakeholders on previous public health guidance and invite them to register an interest in any new topics relevant to them. We also contact organisations that have not been involved with NICE public health guidance before if we think they may have an interest in the topic. Previous and potential stakeholders are also notified if NICE is planning to update an existing piece of public health guidance.

Any organisation can register as a stakeholder if it fits into one of the groups listed in the 'What is a stakeholder?' section – it does not have to be

approached by NICE first. Organisations can register an interest in a specific guidance topic at any time during its development. A registration form is on the NICE website:

www.nice.org.uk/ourguidance/niceguidancebytype/publichealthinterventionguidance/stakeholderregistration/ph_shreg_form.jsp

It is important that organisations register their interest for each piece of guidance.

Recruiting committee members

Public Health Advisory Committees (PHACs) are the standing committees responsible for the development of NICE public health guidance (see Factsheet 1). Each committee includes at least two people who bring community perspectives to the work – 1 core member and 1 topic expert member.

Vacancies for PHAC community members are advertised on the NICE website for 4 weeks. For topic expert community members, vacancies are published either during the scope consultation period (see below) or when the final scope has been published.

The Public Involvement Programme asks stakeholder organisations to let people in their networks know about vacancies and to encourage eligible people to apply for community membership. For more information about the recruitment process and the role of community members of these committees, see Factsheet 3.

Developing the guidance

Drafting the scope

The topic areas to be covered by the guidance are set out in a document called the 'scope' which broadly outlines what the guidance will and will not cover (see Factsheet 1). NICE invites all registered stakeholder organisations to comment on the draft scope during a 4-week consultation period.

Stakeholder meetings

By exception, where a guidance topic or an area of practice has unique complexities or the topic is new to NICE, a stakeholder meeting may be held. NICE will invite all stakeholder organisations to attend the meeting during consultation on the draft scope. If there is a stakeholder workshop for the guidance topic you are interested in, you will be sent a first draft of the scope, which will be discussed at the meeting. Your organisation can send two people to the meeting and we encourage you to send someone who has knowledge of and can represent the interests of people who will be affected by the guidance, which may include the public, specific communities or groups, patients, service users or carers.

The meeting is an opportunity to:

- find out more about:
 - what NICE does
 - how NICE develops its public health guidance
 - opportunities for stakeholder organisations and others to contribute
- discuss the draft of the scope
- hear other stakeholders' views on the key issues that the guidance will cover.

The stakeholder meeting does not replace the formal process of submitting comments via the official email address for the project. This is explained in more detail below.

Stakeholder comments on the scope during the consultation

As a stakeholder you will be sent a website link to the draft scope with information about the deadline for comments. NICE greatly values the comments of organisations representing community interests about the draft scope alongside those of public health professionals, academics, commercial organisations and others during the consultation period.

To make sure that all stakeholders are treated fairly and that the process has been followed properly, NICE can consider only written comments submitted before the deadline and on the form provided. If you have any questions about

how the scope is developed, or about commenting on the draft scope, please contact the Public Involvement Programme:

Alix Johnson, Public Involvement Adviser, alix.johnson@nice.org.uk, 0207 045 2059

Jess Fielding, Public Involvement Adviser, jessica.fielding@nice.org.uk, 0161 219 3889

Some ideas on what to look for in the draft scope

- Does the scope take account of issues that are important for people whose health should benefit from this guidance (the 'target population') or the wider community who may be affected by the guidance?
- Does the scope mention activities or approaches that the target population or wider community think may be important?
- Are there any groups of people who might need particular consideration? For example in relation to age, disability, ethnicity, sex or gender, religion or belief, sexual orientation, socioeconomic status, where people live or their family situation.
- Does the scope unfairly exclude any groups of people (for instance by their age)?
- If relevant, does the scope take account of the information needs of the target population or wider community, and any related issues of choice or preference?
- Is the wording of the scope sympathetic to and respectful of the individuals or communities who will be affected by the guidance?

Finalising the scope

Following the 4 week consultation period, NICE considers all the stakeholder comments and produces a final version of the scope. Five days before this is published, NICE contacts stakeholders to check that all their comments have been included and have been correctly understood.

NICE uses the scope to search for evidence and develop draft guidance (see Factsheet 1).

Evidence from stakeholder organisations

During development of the guidance NICE may identify gaps in the evidence for specific areas defined in the scope. If this happens NICE may ask stakeholder organisations about any additional research evidence they may be aware of on these specific areas (stakeholders are usually given 4 weeks to respond to this invitation).

Such evidence could include information on the impact of the health issue on people's lives, or the views and experiences of specific groups (or the wider community) about relevant public health activities, or the difference a particular type of intervention might make. This information might come from, for example, well designed studies that you know about (perhaps involving interviews, focus groups or surveys) that might be missed in a literature search of published work in scientific journals. If NICE calls for evidence, we will specify the type of evidence we are looking for, so you can check that any research you have identified fits our criteria before submitting it.

Commenting on the draft guidance

Once draft guidance has been produced, it is put on the website for consultation and stakeholders are invited to comment.

We tell stakeholder organisations well in advance about the consultation dates (which are also available on the NICE website:

www.nice.org.uk/Guidance/PHG/InDevelopment). Shortly before the consultation starts, your organisation will be sent an email with links to the draft guidance, and information about the deadline for comments. The consultation period is normally 6 weeks.

To make sure that all stakeholder organisations are treated fairly and so it can be seen that the process has been followed properly, NICE can consider only written comments submitted before the deadline and on the form provided.

If you have any questions about guidance consultations, or about commenting on the draft guidance, please contact the Public Involvement Programme (see 'Stakeholder comments on scope during consultation' section above for contact details).

The consultation

The draft guidance includes the draft recommendations, details of how they were developed and information about the evidence on which they were based.

This is your organisation's only opportunity to comment on the content and wording of the guidance. It is important that community views are included at this stage, especially if your organisation has concerns about any of the draft recommendations.

Please note that we are unable to accept:

- more than one response from a stakeholder organisation
- comments received after the consultation deadline
- comments that are not on the correct form
- confidential information or other material that you would not wish to be made public
- personal health information about yourself or another person that might reveal your or the other person's identity
- attachments with your comments form, such as research articles, letters or leaflets. If comments forms do have attachments they will be returned without being read. If the stakeholder resubmits the form without attachments, it must be by the consultation deadline.

Some ideas on what to comment on in the draft guidance

- Does the guidance make recommendations about all the issues from the scope that the people affected by the guidance (the 'target population', and wider community where relevant) consider important?
- Do the guidance recommendations reflect what the evidence says about specific activities or approaches?
- Is there important evidence that you know about that the guidance has not taken into account?
- Do you agree with the recommendations? If not, please explain why.
- Does the guidance recommend action or activities that the target population or wider community might consider unacceptable?
- Do the recommendations clearly show the need to take into account people's preferences, where relevant?
- If relevant, do the recommendations take account of the information and support needs of the target population or wider community?
- Where appropriate, do the recommendations consider the specific needs of different groups of people (for example, children or young people, people from specific ethnic or cultural groups)?
- Are the recommendations clear and unambiguous?
- Is the wording respectful to individuals and communities?
- Does the wording reflect the importance of equal partnership between professionals and service users or communities
- Do you have suggestions for research recommendations to cover any gaps in the evidence about important areas of community experience?

Fieldwork

By exception, NICE may conduct fieldwork in new, complex or sensitive areas. Fieldwork involves researchers talking to people working in the topic area about how easy it will be to put the recommendations into practice, according to their local knowledge and practical experience. This takes place at the same time as consultation with stakeholder organisations.

Participants normally include people from local or regional voluntary or community organisations, but for some topics people from national organisations are included, such as trade unions for workplace guidance.

Depending on time, resources and the nature of the topic, NICE may also contract researchers to consult with members of the target population, to check that the draft recommendations are relevant and acceptable to them.

After the consultation and fieldwork

The people developing the guidance take into account the fieldwork report and comments from stakeholders, and amend the guidance as necessary. On the day of publication, NICE sends all the responses to stakeholders to check that all their comments have been included and understood. After the guidance is published, NICE posts a table of all stakeholder comments and its responses to them on its website.

Publishing guidance

NICE publicises its guidance (see Factsheet 1), with other documents designed to help make sure the recommendations are put into practice (see Factsheet 5).

Many terms in this factsheet are described in the NICE website glossary – www.nice.org.uk/website/glossary