



Developing NICE guidelines: how to get involved

Audit and service improvement

Published: 31 October 2014

Last updated: 31 October 2018

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Introduction

NICE guidelines are developed by several groups working together; a developer who finds and summarises the evidence, a committee who discuss the evidence and make recommendations, and NICE staff who check the quality of the guideline. Stakeholders are organisations that have registered with us because they want to get involved in developing a guideline.

How we develop NICE guidelines

NICE guidelines are based on the best available evidence. We also rely on input from experts from the NHS, social care, local authorities and other organisations in the public, private and voluntary sectors. The views of people who use health and care services, and representatives of communities affected by the guideline, are essential to make sure the recommendations cover issues that are important to them.

NICE guidelines are developed by committees who take into account ethical and moral issues when making judgements and writing recommendations for NICE guidelines.

We have an obligation to promote equality and consider how our guidelines might affect groups with characteristics protected by the Equality Act (2010): age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex and sexual orientation. When developing guidelines, we also consider socioeconomic status, and issues affecting groups such as looked-after children, people who are homeless, people who misuse drugs and people in prison.

See our key principles in [developing NICE guidelines: the manual](#) for more information on this.

There are 3 main ways you can get involved:

- Join the committee working on a guideline (see [joining a committee](#)).
- Comment on the draft scope and draft guideline (see [advising and commenting on a draft scope](#) and [commenting on a draft guideline](#)).
- Provide evidence if the guideline developer makes a 'call for evidence' (see [answering a call for evidence](#)).

In addition, people are sometimes asked to contribute in other ways, such as giving expert testimony to the committee or taking part in a focus group, interview or survey.

The main stages of guideline development are summarised in the next section on [stages of guideline development](#).

Stages of guideline development

Scoping

- The developer drafts the guideline scope.
- The draft scope is placed on the NICE website (for 4 weeks) for consultation with stakeholders. Stakeholders comment on the scope (see [advising and commenting on a draft scope](#)) and may attend a scoping workshop.
- The final scope is published on the NICE website.
- The guideline committee is recruited and you can apply to join (see [joining a committee](#)).

Development

- The committee agrees questions for the guideline and the developer looks for evidence and prepares cost analyses.
- The committee discusses the evidence and makes recommendations.
- If no evidence is found, the developer may ask for evidence from people who use services. You could get involved in this way (see [answering a call for evidence](#)).

Consultation

- The draft guideline is placed on the NICE website (for 4 to 6 weeks) for consultation with stakeholders.
- Stakeholders send their comments on the draft guideline to NICE.

Revising the guideline

- The committee discusses the stakeholders' comments and makes changes to the guideline. In this way, stakeholders can inform the final guideline.

- The developer writes replies to all the stakeholder comments.

Publication

- NICE signs off the guideline for publication.
- Stakeholders are sent a confidential advance copy of the guideline just before publication.
- The guideline is published on the NICE website along with the stakeholder comments and responses.

Updating

- NICE carries out regular checks to see if the guideline needs updating.
- Stakeholders and individuals can tell NICE if a guideline might need updating.

Joining a committee

Committees are recruited to develop and update our guidelines. They are made up of a diverse range of members, including people who use health and social care services, carers, and experts in health and social care.

For more information, see [our committees](#) on the NICE website.

The public involvement programme (PIP) at NICE provides training and support to lay members on our committees. See [what lay members do](#) on our website for more information.

Advising and commenting on a draft scope

The scope explains what the guideline will and will not cover.

We sometimes invite registered stakeholders to a workshop to advise us on key issues for the guideline. We usually invite each organisation to nominate 1 person to attend the workshop, so that we can hear views from a wide range of organisations. After the workshop, the draft scope is finalised and put on our website for consultation (usually 4 weeks).

We email registered stakeholders to invite them to comment. We include information and questions to help us find out what stakeholders think about specific issues. See box 1 on 'things to think about' for tips on what to comment on.

Consultation dates are given on the NICE website and you can sign up for our monthly newsletter.

Box 1 Commenting on the draft scope: things to think about

Does the scope:

- Cover issues important for people affected by the guideline?
- Include medicines, procedures and other treatments or options for care that may be important?
- Include treatments or other interventions that are currently used, but may not be effective, acceptable or tolerable to people using services?
- Note any equality issues or aspects of care or services that the guideline should address (for example, cultural differences that may affect the use of an intervention or approach to care)?
- Promote equality of opportunity regardless of age, disability, sex, gender, gender identity, ethnicity, religion and belief, sexual orientation and socioeconomic status?
- Unfairly exclude any groups (for example, by age or general health)?
- Use wording that is respectful of people using services, carers and people working in health or social care?
- Explain how the guideline will fit with government policies?
- Identify other major related projects (such as promotional campaigns) that should be used when developing the guideline?

Make your comments as clear and specific as possible, explaining the reasons behind any changes you suggest.

Answering a call for evidence

The developer may make a 'call for evidence' if they think there may be useful evidence that they won't find with their evidence searches.

The evidence may include information on how a condition affects people's lives, or how people or their carers feel about their care.

The developer invites stakeholders and individuals to provide evidence, and posts the invitation on our website. See [developing NICE guidelines: the manual](#) for more information.

Commenting on a draft guideline

Consultation is a crucial part of developing a guideline. Comments from stakeholders help us to make sure the guideline is accurate and relevant to people who will be using it and to people using services.

We put the draft guideline on our website for consultation (for 4 to 6 weeks).

We tell registered stakeholders that the draft is available and how to submit comments. We want stakeholders' views on important issues, such as how easy it will be for people to follow the recommendations. See box 2 on 'things to think about' for tips on what to comment on.

If your organisation and another stakeholder have similar views on the guideline, we encourage you to send a joint response.

The developer will acknowledge each comment and answer it as completely as possible. The committee considers whether changes to the guideline are needed because of the consultation comments. If changes are made, this is made clear in the response to the comment. If no changes are made, the response to the comment explains why not. Comments and the responses are then published on the NICE website with the revised guideline.

We encourage individuals to comment by contacting a stakeholder organisation. If you send comments direct to us, the committee will consider them but we won't publish a response.

Box 2 Commenting on the draft guideline: things to think about

The recommendations

How well do the recommendations:

- cover the issues in the scope
- reflect what the evidence says
- take account of the choices and preferences of people affected by the guideline, and the information and support they need
- consider the needs of different groups (for example, children and young people, and people from black, Asian and minority ethnic groups)
- use wording that is clear, easy to follow and respectful
- identify the right individuals and organisations to take action, and reflect the importance of working together
- promote equality of opportunity?

Do the recommendations include anything that people affected by the guideline might find unacceptable?

The evidence

- Are there any possible inconsistencies or disagreements about how the committee interpreted and applied the evidence?
- Tell us about any other evidence that should be included.
- Do the research recommendations cover the important gaps in the evidence?

Implementing the recommendations

- Which recommendations could have the biggest impact and which would be the most challenging to put into practice?
- What would help users overcome these challenges? Are there existing resources or examples of good practice?

What you need to do as a stakeholder to comment

- Register your organisation as a stakeholder – see [register as a stakeholder](#) on our website.
- Choose a contact to coordinate comments in your organisation.
- Circulate the draft in your organisation if appropriate, making clear that it is for consultation and asking people to respond to the contact (rather than directly to NICE).
- Combine the comments into 1 response from your organisation using the form provided and include the name of your organisation and contact in your response.
- Highlight and underline any confidential information in your comments.
- Send the comments by the closing date to the dedicated email address for the topic.

ISBN: 978-1-4731-0828-8