Reviewing a draft SIGN guideline

Information for patients, carers and members of the public
Who are we?

The Scottish Intercollegiate Guideline Network (SIGN) is part of Healthcare Improvement Scotland, which is a public body that:

- provides advice and guidance to the NHS in Scotland, and
- inspects hospitals and helps them to improve what they do to make sure they are safe and clean.
What do we do?

We develop guidelines for health and social care staff in Scotland to:

- help professionals, service users, carers and patients understand scientific evidence so they can use it to make decisions about a person’s care
- help people to get the best care available, no matter where they live
- help to improve the quality of health and social care across Scotland.
Who decides which guidelines are needed?

Anyone in Scotland can suggest a topic for a guideline. This includes health and social care staff, voluntary organisations, charities, people with lived experience (patients, service users, and carers) and members of the public.

We choose a topic if we know that hospitals or general practitioners (GP) in different areas of Scotland offer different tests and treatments for the same condition, especially if this leads to different results for people. We also select particular topics if there is uncertainty over which treatments work best to reduce the effects of a disease or the number of deaths associated with conditions or disabilities.

To suggest a guideline topic you can visit our website and fill in our topic proposal form [www.sign.ac.uk/get-involved/propose-a-topic](http://www.sign.ac.uk/get-involved/propose-a-topic)
Who is involved in developing guidelines?

To develop a guideline, we bring together a group of people from across Scotland. The guideline development group includes:

- NHS staff, for example hospital doctors, nurses, GPs, psychiatrists and physiotherapists
- staff from areas such as education and social work
- people with lived experience, and
- voluntary sector representatives.
What are your guidelines based on?

Our guidelines make recommendations for how to treat and support patients with a particular condition.

The recommendations are based on a combination of scientific research and lived experience. If no research has been done, the guideline highlights this as an area where more research is needed.
Why do we ask people to review our guidelines before they are published?

All our guidelines are independently reviewed by other health and social care staff and academic experts before they are published. Draft guidelines are also reviewed by people with lived experience, who can provide us with comments from their perspective. We ask reviewers with lived experience to comment on the guideline, in particular on:

• whether the guideline is person-centred, for example does it reflect the views and experiences of people with lived experience?

• the way the guideline development group has interpreted the evidence

• whether the recommendations are clear and easy to understand

• whether the guideline is useful.
We also ask the reviewers to suggest improvements to the guideline.

We put all the comments from reviewers into a report. The guideline group discusses this and we make changes to the draft guideline, if appropriate. If no changes are made we will record the reasons for this. Before publishing the guideline, the SIGN editorial team checks that the reviewers’ comments have been addressed. We publish the report with the guideline.
Who can participate as a reviewer?

We invite health and social care professionals and at least two people with lived experience to review our guidelines.

People with lived experience are recruited from voluntary organisations or through SIGN’s patient and public involvement network. We also have open consultation for each guideline, where the draft guideline is on our website for one month. We advertise this opportunity to comment on the draft guideline to patient groups most likely to have an interest in the topic. Anyone can comment on our guidelines during open consultation.

If you have been invited to review a guideline but can’t commit to doing it, you are welcome to suggest an alternative reviewer. You can do this by replying to the email invite to let us know.
How should I start reviewing a draft guideline?

SIGN guidelines are large documents so following a series of logical steps is a helpful way to review a draft guideline.

There is no right way to review a guideline.

The approach you take will depend on you as an individual. It is difficult to say how long it will take you to review a guideline as everyone reads at different rates and will use different approaches to review it.

You will be given four weeks to review the guideline so you may want to do this in stages.

The following approach is one that you may want to consider:

Gather your thoughts and ideas

• Get a general idea of what the guideline is about
• Look through the guideline first
• Look at the contents and chapter headings
• Read the introduction.
You may want to consider the following questions. Each guideline covers specific issues so not all of these questions will apply to every guideline.

- What does the title mean to you?
- Are you aware of this condition?
- What questions might people have about the condition or treatment?
- Have you heard from people with lived experience about their condition? For example treatments they might be considering?
- What outcomes might they be hoping for? What side effects might they be concerned about?
- What aspects of treatment and care might be particularly important to people living with the condition?
- Are you aware of people and their carers being given any information or support?
- Is it clear where people can find appropriate support and advice?
- Who might want to know about the conclusions and recommendations of the guideline?
- What is your overall impression of the guideline?
- Is it clear how we have engaged with people with lived experience to reflect their experiences and perspectives in the guideline?
Review the guideline

Read the draft guideline carefully and consider it in the light of your own experience and expertise. It may be helpful to make some notes.

When you think you understand the guideline you could try rewriting the main ideas in plain language or imagine trying to explain them to a friend. Ask yourself if it still makes sense.

- Are the various sections clearly titled?
- Is there a logical thread to the guideline?
- Do you think the guideline is relevant to people with this condition and their carers?
- From the perspective of someone living with the condition, what might be the challenges of the treatments recommended?
- Are there patient outcomes that should have been considered?
- Is the language clear and accurate? Is there alternative, preferred language?
- Are some sentences long or difficult to understand?
- Are there any unnecessary abbreviations and is there too much jargon?
- Are there any technical words and phrases that need to be explained?
Can you work out the likelihood of a person benefiting or experiencing harm from the treatment being suggested?

Are other findings, for example side effects, clearly reported?

Are there any sections in the guideline that you think are particularly well written?

Is there anything missing or anything you expected to be covered which is not?

Please comment on the sections providing the perspective of people with lived experience we have engaged with

- does this reflect your own experiences or those you represent?
- what do you think of any quotes we have included from people with lived experience?

**Provision of information sections**

These sections are designed for professionals to use when they discuss a condition with people with lived experience of the condition. We include this information to promote shared decision making. Our guidelines may also include ‘information for discussion’ points throughout the guideline. We particularly ask people with lived experience to comment on these sections by answering the following questions:

- Is there is any jargon or any technical terms that we need to explain?
- Is the tone of this section acceptable?
- Does the wording deal with the condition sensitively?
• Is the information useful for people with lived experience of the condition?

• Are the information for discussion points throughout the guideline helpful? Is there anything missing?

Submit your comments

In your invitation to review the guideline you will be given a link to an online form for returning your comments. If you are taking part in open consultation, this link will be on SIGN’s website. Please submit comments by the deadline highlighted. The link takes you to a feedback form which allows you to submit comments relevant to each section of the guideline. There are no specific questions in the form, so you can add whatever you want to say. You only have to add comments into the sections where you want to give feedback. There is space at the end for general comments about the guideline.

In preparing your review it may be helpful to look back at your notes and, bearing these in mind, consider the following issues as a checklist for your review.

• If you had any questions have they been answered?

• Can you suggest changes to how the guideline has covered the topic or how it is written?

• Have you given us positive feedback as well as negative?

When possible, it would be helpful if you try to suggest changes which could improve the text. Explain why you recommend doing it differently and why it is important.
Declarations of Interest (DOI)

We ask all reviewers to complete a declaration of interests form. This is so we can identify any interests that you have which could influence your view on the content of the guideline. The form is at the start of the form for submitting your comments online.
What do we mean by a conflict of interest or a competing interest?

A conflict of interest or a competing interest is an interest which may (or may be thought by others) to influence your judgement on the content of the guideline under discussion. For example if you are involved with an organisation that campaigns for a particular type of therapy that might be approved in the guideline; or if you have shares in a pharmaceutical company that makes a medicine that might be recommended in the guideline.

What happens to the declaration of interests forms?

The information you provide will be securely stored for three years by Healthcare Improvement Scotland. After three years your information will be deleted. Your interests will not be published under any circumstances. Your interests do not fall under the scope of the Freedom of Information Act 2000 and will not be disclosed if a Freedom of Information request is made.
Equalities monitoring

We want to make sure that everyone has an equal opportunity to get involved with our work so we ask reviewers to complete an equalities monitoring form to help us to understand who we have engaged with. The questions in this form are voluntary but the more information you give us, the more we can learn about people’s views on the guideline and how we can improve to meet diverse needs.
Will I get feedback on my comments?

A consultation report recording reviewers’ comments and the guideline group’s responses is published on the SIGN website alongside the final guideline.

You will be sent a link to the webpage for the guideline and supporting materials when they are published.

As a gesture of our appreciation, we acknowledge all reviewers in the published guideline.
If you would like a copy of this booklet in another format such as large print, please email sign@sign.ac.uk