Peer reviewing a SIGN guideline: a guide for people with lived experience, non-clinical professionals and 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
- inspects hospitals and helps them to improve what they do to make sure they are safe and clean.

What does SIGN do?

We develop guidelines to help:

- health and social care staff, service users, carers and patients understand scientific evidence so they can use it to make decisions about a person's care
- improve the quality of health and social care no matter where they live in Scotland.

Who decides which guidelines are needed?

Anyone in Scotland can suggest a topic for a guideline. This includes health and social care staff, third-sector 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 or treatments for the same condition, especially if this leads to different results for people. We also select 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. If you would like to have an informal chat with someone before filling out the form or if you need help to do this, let us know by emailing sign@sign.ac.uk and we will get in touch.

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
- third sector representatives.

What are our 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. The guideline development group decides what aspects of the condition the guideline will

cover (called the 'remit'). The group then produces a set of 'key questions' about how to manage the condition. 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 be 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 third-sector organisations or through SIGN's patient and public involvement network. You do not need to have medical or scientific training to review our guidelines. What we ask for and value is your perspective on the issues and outcomes that are important for people with lived experience and the public. By reviewing our guidelines, you will be giving the guideline development group a valuable real-life perspective on patient-focused aspects of the guideline, drawing on your own or others' experience of a particular condition, or intervention.

If we invite you to review our guideline, we will send you an email. You will be asked to accept or decline the invitation by replying to the email. If you are unable to review, please let us know, and if you can suggest an alternative reviewer that would be most helpful.

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, carer or service user groups most likely to have an interest in the topic. Anyone can comment on our guidelines during open consultation.

What data will you collect from me?

We will collect and store the following categories of data.

- Your name and title
- Your address and email address

- Your opinions and experience provided in your review.

We ask all reviewers to complete a declaration of interests form. This is so we can identify any interests that you have that could influence your view on the content of the guideline. The form is at the start of the form for submitting your comments online.

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.

The information you provide will be stored securely 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.

We also collect and store special categories of personal data (which includes health information and other sensitive personal data that you may choose to share with us, either in your equalities monitoring information or in your peer review comments. The equalities monitoring form helps 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.

How should I start reviewing a draft guideline?

There is no right way to review a guideline. The approach you take will depend on you as an individual but when commenting it is important that comments stay within the scope of the guideline and don't veer off subject. Not all things you will include in your comments will be positive, but it is important to be unbiased, respectful and constructive when reviewing a guideline. Personal attacks that call a particular healthcare professional's character or actions into question should never be included in peer review comments.

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. SIGN guidelines are large documents so following a series of logical steps is a helpful way to review a draft guideline. 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?
- Has the guideline considered equality issues?
- 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 who 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 about treatment and care options. Our guidelines may also include ‘information for discussion’ points throughout the guideline. We ask people with lived experience to comment particularly on these sections by answering the following questions:

- Is there 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?
- Are you aware of further sources of information that are 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 the 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 that allows you to submit comments relevant to each section of the guideline. Sometimes there are specific questions in the form to help the guideline group get the feedback they need. Otherwise, the sections of the form relate to the sections in the guideline and allow you to give whatever feedback you want. 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 that could improve the text. Explain why you recommend doing it differently and why it is important.

Will I get feedback on my comments?

We are unable to give personal feedback to reviewers because of the volume of peer review comments we get and tight time constraints. 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.