

What skills do I need?

You do not need any formal qualifications, but it may help if you have some of the following.

- Direct experience of the guideline condition (for example, as someone who has or has had the condition, or the carer or family member of someone who has the condition).
- An understanding of the needs and concerns of a wider network of patients (for example, as a member of a support group).
- Time to commit to the work of the group (for example, go to meetings, do background reading and comment on drafts).
- A willingness to give the views of patient and carer groups who are not represented on the guideline group.
- Some experience of working in large groups.
- Good communication and team-working skills.
- Enthusiasm and commitment.

Will I be offered support?

We support patient and carer representatives by:

- recruiting at least two patient and carer representatives to each group;
- offering an informal introduction to SIGN;
- holding training days for patient representatives;
- providing phone and e-mail support;
- giving clear guidance on their role in the development group;
- awarding membership of the patient network of user representatives, which includes patient support organisations, (members of the patient network will receive our newsletter twice a month); and
- refunding travel and any-care related expenses.

Have you ever thought to yourself, "Nobody ever listens to me"?

By joining a SIGN guideline development group, you will be given the opportunity to make a contribution to delivering care in the NHS and have your voice heard.



Contact details

If you need more information about getting involved with SIGN, please contact:

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SIGN

NHS
Quality
Improvement
Scotland

Patient involvement in SIGN guidelines



Background

What is SIGN?

The Scottish Intercollegiate Guidelines Network (SIGN) develops evidence-based national guidelines for the NHS in Scotland.

SIGN covers many areas of health care. Our board includes doctors, nurses, pharmacists, dentists, physiotherapists, dieticians, occupational therapists and patient representatives.

What are SIGN guidelines?

Our guidelines are designed to help healthcare professionals keep up with and understand the ever-increasing amount of research being done into best treatments and the causes of disease. They help healthcare professionals and patients make decisions about the best health care in specific situations. Our guidelines are based on the best medical and scientific evidence that is available.

The guidelines make clinical recommendations that are that are graded **A**, **B**, **C** or **D** to show the strength of the supporting evidence. Good-practice points are given to highlight specific aspects of accepted clinical practice which there is no evidence for.

What is patient involvement?

Patient involvement means involving patients, carers and their representatives in their own care, and in planning, monitoring and developing health services. Patients and carers may have different views about getting the most from the NHS than healthcare professionals.

Why involve patients?

We involve patients and carers in developing guidelines to identify their concerns and allow their views to complement the knowledge and experience of healthcare professionals.

Working with SIGN

How do patients and carers become involved?

We invite voluntary organisations and members of our patient network to suggest people they think could join a development group. The people who are put forward must give us a short personal statement explaining why they are interested in the group and what experience and skills they could bring to the group. We will consider the statements and choose two members for the group. We will invite new patient representatives to an informal meeting with patient involvement staff before the first group meeting.

What would I be asked to do?

As a member of a guideline development group, you will use your experiences and views to influence the group's work. This may include:

- going to group meetings every two or three months for about two years;
- making sure that questions about patient treatment take account of issues that matter to patients and carers;
- identifying areas where patients and carers feel care could be improved;
- making sure that the views and concerns of patients are reflected in the guideline;
- helping to write the information for the patients' section of the guideline;
- raising awareness of patient and carer issues at the national open meeting; and
- helping to make sure that the guideline is sensitively worded.

How much of my time would it take?

You can choose how much you want to get involved in the guideline development process. You can choose from the following.

Full group member: You can go to all the group meetings over a two-to three-year-period.

Key stage member: You can only be involved at certain stages of developing the guideline. You could go to all the group meetings until the main questions are finalised (two or three meetings). You could also go to the national open meeting and nominate a public representative to review the draft guideline.

Advisor: You could have in-depth knowledge of the condition but not be able to commit yourself for the lifetime of the group. You would be asked to go to the first two meetings of the development group and would be happy for the group to contact you at other stages of the guideline development process to help advise on issues.

How else could I get involved?

- **Comment on a draft guideline:** A limited number of free spaces are available for patients and carers at the national open meetings, which are held to discuss each draft guideline.
- **Review a draft guideline:** Patient representatives are invited to take part in the formal review of guideline development to make sure that the guideline has considered issues that are important to patients and carers.

