

Module 2: Guideline development groups

The guideline development group

Guideline development groups include:

- NHS staff, for example, hospital doctors, nurses, GPs, psychiatrists and physiotherapists
- staff from areas such as education and social work
- lived experience representatives (people living with conditions, service users, unpaid carers and family members)
- third sector representatives

The guideline development group's goal is to create practical advice based on evidence and their own experience, while considering what's best for people affected by conditions.

Groups usually have 15 to 25 members, each representing a specific area and field of expertise.

Each member of a guideline development group represents both a geographical region and a speciality or professional group. The guideline development group has a mix of the following experience and skills:

- clinical expertise, such as nursing
- other specialist expertise, such as social services
- a practical understanding of the problems faced when providing care
- communication and team working skills, and
- critical appraisal skills.

Members of the guideline group, despite their different expertise, have equal status.

A healthcare professional chairs each group. The group's duration varies from 3 to 18 months, depending on the project type, for example an update. They meet every couple of months on average, sometimes more for smaller groups.

Groups look at the research and create guidelines based on evidence, recommending treatments based on effectiveness.

Responsibilities of guideline group members

Group Chair

The Chair of a guideline development group plays a vital role in making sure everyone works together well and finishes the guideline on time and within budget. The Chair:

- makes sure everyone participates in discussions

- pays attention to how the group discuss issues and makes decisions
- solves any problems that come up in meetings
- support lived experience representatives by making sure their input is respected and encouraging them to share their thoughts.

The Chair also meets lived experience representatives before the first group meeting to discuss any issues and answer questions that people may have.

Other guideline development group members

Members of the guideline development group must fully commit to the group's work and tasks, letting the Chair know if they have any concerns. Their main jobs are to:

- identify important issues and make questions for review
- read papers and evidence and write recommendations
- be responsible for specific parts of the guideline
- check the guideline for accuracy and relevance
- help respond to feedback on the draft guideline
- tell SIGN about any new research after the guideline is published.

Lived experience representatives

We believe it is very important for people with lived experience to be involved in the decisions that are made about their care. By involving them in the guideline development process, we can understand their concerns and use their insight alongside scientific research and professional knowledge.

Lived experience representatives can help the guideline development group understand what it is like to live with a condition and how treatments affect their lives.

Lived experience representatives can:

- Make sure important questions come from real issues people face.
- Identify what outcomes matter for these questions.
- Remind others about limitations in scientific findings related to things like age, disability or gender.
- Make sure the group thinks about specific needs, like information, support and communication.
- Raise other issues to make sure everyone's needs are considered. For example, someone's religion might affect what treatment they can have.
- Help the group use clear and sensitive language in the guidelines.
- Speaking at national meetings.
- Finding people with lived experience for peer reviews.
- Assisting with consultations.
- Spreading the word about the guideline.

Recruitment of lived experience representatives to guideline groups

- We ask for at least two people with lived experience to join guideline groups.
- We get nominations from third sector groups in Scotland, and we also advertise the opportunity on Volunteer Scotland. This lets anyone interested take part, not just those who are involved with organisations, so guidelines reflect different experiences and needs.
- If we talk to people with lived experience directly, like in a focus group, they might become future representatives.
- We give details about the role, support, commitment needed and what makes a good representative. This helps people make informed nominations and apply.

How we choose people with lived experience to sit on guideline groups

To choose people with lived experience, we:

- review all the applications we get
- compare the role description with what applicants offer
- consider their experiences and skills, for example, a support group member might be good at teamwork.

We prefer to choose someone with a condition because they know firsthand what it's like to live with a condition. If someone's application isn't chosen, we might still involve them in other parts of the process.

We want to work with people from different backgrounds. We encourage applications from those with disabilities, ethnic minorities, young people and other groups not well represented.

Do the quiz

To complete this module, take a few minutes to do the end-of-module quiz. It's a quick way to make sure you've learned everything you need.