# SIGN 100: A resource for people with lived experience and the public.

January 2025

# Contents

## Introduction

Welcome to SIGN 100.

SIGN 100 offers an introduction to SIGN. It is designed for people with a non-clinical background taking part in guideline development.

SIGN 100 aims to:

- explain how we develop clinical guidelines for the NHS in Scotland
- explain the methods we use to develop clinical guidelines
- help you understand how we involve people with lived experience and the public in our work.

Throughout SIGN 100, we've used the term “people with lived experience” to refer to those involved who have first-hand knowledge of conditions, such as:

- people living with conditions
- service users
- unpaid caregivers
- family members and friends of people with conditions

This is the PDF version of the online training modules, which can be found at https://www.sign.ac.uk/patient-and-public-involvement/sign-100-training/

# Chapter 1: About us

## Who are we?

- We are the Scottish Intercollegiate Guidelines Network (SIGN).
- Our goal is to make healthcare better for people in Scotland by ensuring consistent, evidence-based guidelines for treating them.
- We work with health and social care professionals, third sector organisations, the public and people with lived experience.
- Our guidelines are there to help professionals and people living with conditions make decisions about treatment. We want to make sure that everyone can understand them, so we also create plain language versions. Making decisions together is known as Realistic Medicine. It puts you at the centre of decisions made about your care.

## SIGN Council

- SIGN Council members make operational decisions for how SIGN functions.
- Members of SIGN Council are chosen by their Royal College or another professional group. They represent different specialties and talk to other experts in their field.
- Some members of SIGN Council help with the development of guidelines. They might join advisory groups or help with editorial review.
- We also have public partners (volunteers) from Healthcare Improvement Scotland who represent people with lived experience and the public. They also sit on the Public Involvement Advisory Group (PIAG) where they help shape our work.

## SIGN Executive

- This is the name for the team of staff within the Evidence Directorate of Healthcare Improvement Scotland we employ to run the organisation.
- The staff are responsible for putting SIGN Council's decisions into practice.
- The staff carry out the guideline programme on time and in line with SIGN's budget.
- The SIGN team works closely with other parts of Healthcare Improvement Scotland (HIS) and keeps to HIS policies and procedures.

## What are our guidelines for?

We want to make sure that everyone in Scotland gets the best health care, so our guidelines recommend the best treatments backed by evidence. So, we write guidelines to:

- help professionals, the public and people with lived experience understand medical 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.

## What are our guidelines based on?

Our guidelines are based on the most up-to-date scientific evidence. We analyse the available research evidence for the best way to diagnose, treat and care for people. If no research has been done, health and social care professionals can use their experience and judgement to suggest treatments. They will highlight this as an area where more research is needed.

More information on research and we use it to develop guidelines can be found in Chapter 3.

## Who decides which guidelines are needed?

Anyone in Scotland can suggest a topic for a guideline. We welcome suggestions.

To suggest a guideline topic you can visit our website and fill out our support request form. We review these suggestions through a process at Healthcare Improvement Scotland. If you suggest a topic our Patient Involvement Advisor and SIGN Public Partners can help you to complete the application. We also ask healthcare professionals to share their thoughts on the suggestions.

We choose a topic if we know that different hospitals or professionals offer different tests and treatments for the same problem. We also choose topics when we're not sure which treatments work best for certain conditions.

Before we start producing a guideline, we make sure there's enough evidence to support it. Our team looks at lots of scientific research to find the best information. This ensures that our guidelines are trustworthy. Once a topic is approved, we decide what it will and won't cover. This helps keep our guidelines focused and helpful.

## How do we decide what the guideline will cover (scope)?

We decide what our guideline will focus on based on the topic suggestion and any research we've done. We also listen to people and engage with people who have personal experience with the topic.

## Consulting third sector organisations

We invite organisations and charities that represent people with lived experience to tell us about the issues (including inequality issues) they think the guideline should deal with, and their reasons for making these suggestions. They might share stories from their members or information from surveys.

## Consulting the SIGN Patient and Public Involvement Network

We also ask members of the SIGN Patient and Public Involvement Network for their input. Many of them have firsthand experience with the topics our guidelines cover. They share what they think is important.

**Consulting people with lived experience**

Sometimes our literature searches find a lot of evidence, but we don’t have enough feedback from organisations that represent people with lived experience. In these situations, we may consider other ways of getting information. We may talk to people with lived experience through focus groups or by attending support group meetings. This helps us make sure our guidelines reflect real needs and concerns.

**Engaging with people through social media**

We use social media to ask people what they think our guideline should cover.

We gather all the information from the methods we've used and share it with the guideline development group at their first meeting. They use this information to decide what questions the guideline should try to answer.

The guideline group doesn't have to include every issue raised by people with lived experience but they must explain why if they decide not to include something.

We also do an Equality Impact Assessment (EQIA) as part of planning the guideline. This makes sure we consider how our recommendations might affect different groups of people. We want to make sure our guidelines don't harm anyone because of their race, gender or other protected characteristics.

**Who funds the guideline development process?**

Healthcare Improvement Scotland is funded by the Scottish Government. This money helps with:

- paying the staff of the SIGN Executive
- covering costs like library fees and meeting expenses for guideline development groups
- supporting the consultation process
- paying for printing and sharing of plain language versions of guidelines.

People who work on SIGN guideline development groups don't get paid. But independent practitioners can claim locum payments and travel costs. Lived experience representatives can also get travel, food, child care and other expenses to attend meetings. You can find more details on how to claim expenses in the Volunteer guide.

**Do you look at how your recommendations can affect NHS resources?**

The NHS doesn't have a lot of money to spend, and things keep getting more expensive. So, it's important to think about whether the benefits of a treatment are worth the cost.

We look at information about costs and benefits in special databases. A Health Economist helps with this. They study how much treatments cost and how well they work. We use this information to decide what to recommend.

If the guideline group suggests something that might cost a lot or change how a service works, the Health Economist can work out how much it might cost.

# Chapter 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.

# Chapter 3: Using research to develop guidelines

## What is “research” and what is “evidence”?

Since our guidelines are based on medical and scientific research, we thought it might be helpful to explain the basic principles of research. Having an understanding of the research process and the different types of research may make it easier to contribute to the guideline development process.

Research is about looking for new information that could help us make better decisions about treatments or policies. Researchers use different methods like surveys, experiments or interviews to collect and analyse data. They ask questions, gather information, study it and then share their findings.

There are two main types of research:

**Qualitative research**: This type of research tries to understand why people think or behave in certain ways. It doesn't focus on numbers but explores people's experiences and beliefs. Qualitative researchers might use methods like interviews or focus groups.

**Quantitative research**: This research collects data in numbers. It might ask questions like how many people get sick each year or whether a new treatment works better than an old one. Quantitative researchers often use methods like surveys or clinical trials.

The results of both types of research are written up and published in scientific journals.
There are four main types of study we use in our guidelines – systematic reviews, clinical trials, observational studies, diagnostic studies and health economic studies.

**Systematic reviews**

Systematic reviews bring together the results of all the studies that have been carried out around the world in a particular time frame (for example, 2018-2023). These studies will look at a particular research question. The researchers combine the results to give a more complete picture of what the evidence says. Systematic reviews can also tell us about the quality of all the research that has been done.

The vital parts of a systematic review include:

- identifying research papers using clearly defined search methods
- choosing research papers using clearly defined reason for including and excluding information, for example, including studies which only look at people over the age of 18 or excluding studies which look at people with learning disabilities
- assessing research papers against methodological standards

You may hear the term “meta-analysis” when you discuss research papers at SIGN. A meta-analysis is a special type of systematic review that uses statistical methods to combine the results of two or more studies that considered the same research questions in the same way.

**Clinical trials**

Clinical trials are like tests for new treatments. They involve groups of patients who might get a new treatment, an old treatment or sometimes just a fake treatment called a placebo. This helps scientists see if the new treatment works better than nothing or better than what's already out there.

These trials are used to check if medicines or other healthcare methods are safe and effective. There are different types of clinical trials:

- **Randomised controlled trial (RCT)**: This kind of trial compares two groups of people. One group gets the new treatment, and the other gets either the usual treatment or a fake treatment. The decision about who gets what is random, and the people who run the study don't know who gets what. This helps make sure the results are fair and not influenced by personal beliefs.
- **Observational studies**: In these studies, researchers don't do anything to the patients. Instead, they watch what happens naturally. Patients might be grouped by things like whether they smoke or if they have a certain condition. There are different types of observational studies:
- **Cohort studies**: Patients are grouped based on their exposure to something, like smoking and followed for a while.
- **Case-control studies**: Patients are grouped based on whether they have a certain outcome, like cancer and researchers try to find out what might have caused it.
- **Diagnostic studies**: These try to find the best way to diagnose a condition. They might compare new tests to ones already in use.
- **Health economic studies**: These look at how much treatments cost compared to how much they help patients. They help us understand if a treatment is worth the money.

## How are research studies identified?

There are many international databases of scientific and medical research results. These databases help researchers to search for and bring together studies that may be published in different or unexpected journals. The most widely used medical and scientific databases

- **MEDLINE**: This is run by the National Library of Medicine in the USA and has a huge list of journals
- **Cochrane library**: This is managed by the Cochrane Collaboration, a global group that makes systematic reviews of healthcare and looks for evidence from clinical trials and other studies
- **Embase**: This focuses on drugs and clinical medicine, and has better European coverage than MEDLINE
- **CINAHL**: This is a nursing and health-related database that covers all aspects of nursing, health education, occupational therapy, social services and other related disciplines
- **PsychINFO**: This is produced by the American Psychological Association and covers psychology, psychiatry and related subjects

There are two ways to search for research papers in a database:

- Using key words, for example, words in the title or abstract (summary of the paper), authors' names or where the research was published
- Using medical subject headings; This means looking for papers based on specific topics, like heart disease.

**How are relevant research papers identified for guidelines?**
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.

The guideline development group have to be realistic about the number of key questions that can be answered in a single guideline. If the guideline development group set too many key questions, their workload can become too difficult to manage. It is important to limit the guideline scope to those topic areas where there is genuine uncertainty and where implementation of evidence-based recommendations will improve care and reduce variation in practice.

Key questions guide the guideline and are accurately phrased to direct the search and get precise answers. Key questions are broken down onto the structure below to form the basis of search strategies developed by Information Scientists to identify relevant literature.

| **P**opulation | **I**ntervention | **C**omparator(s) | **O**utcomes(s) | **S**etting(s) |
|---|---|---|---|---|
| People to which the question applies, for example age group, sex and whether people are at risk of particular conditions. | Intervention being considered, for example treatments involving medications, medical devices, or diagnostic tests | Alternatives being considered, for example current treatment or standard care | What you want to accomplish, accurate diagnosis or relieve or improve symptoms | Care setting such as as primary care, community, acute or emergency settings should be described |

Our Evidence and Information Scientists use the databases we mentioned earlier to search for papers that are relevant to the guideline. They use the key questions to develop search strategies to search for relevant research papers.

A typical search strategy will identify between 400 and 500 papers. These are presented in the form of abstracts that summarise the paper.

Before we start to critically appraise the research papers, our Evidence and Information Scientist will take out any papers that are clearly not relevant. This is known as the first stage of the study selection process (also known as sifting).

At the second stage of sifting, study abstracts are used to assess if studies are likely to be a potential source of evidence. At the final selection stage, inclusion and exclusion criteria are applied to the full study reports. These criteria are developed from the key question and allow studies to be excluded based on specified factors such as geographical or healthcare context, study methodologies or numbers of participants. The guideline development group provide expert input to the study selection process and reject any that do not meet the conditions the guideline development group agreed.

**Reviewing the research papers**

Once papers have been chosen as possible sources of evidence, the Evidence and Information Scientists will assess the study methods to see how well the study has been done. This assessment is based on a number of questions in a checklist. The questions vary between the different types of study, and we have designed checklists for each type. These checklists bring a degree of consistency to the appraisal process. The questions focus on the parts of the study's design that are known to have a significant influence on whether the results and conclusions are valid.

**What was the research question and why was the study needed?**

The introduction to a research paper should give the background to the research and why the research is being done. The research question is the broad question that the research is trying to answer. If you cannot find the research question in the paper, it tends to suggest that the authors did not have a clear aim and that they may not have designed the study very well.

**How was the study done and was the design appropriate to the question?**

Some studies follow patients up over a period of time – these are known as 'prospective studies.' Others trace what happened to people in the past and are known as 'retrospective studies.' What type of study should have been used depends on the research question. Below are some examples with the research question in bold.

- **How many breast cancer patients die each year?** This question is best answered by a survey as we are interested in numbers of patients.
- **Is cigarette smoking dangerous?** This question is best answered by a cohort study where two or more groups are chosen based on how exposed they are to cigarette smoke, and are followed up over a period of time to see what the outcome is.
- **Does hormone replacement therapy (HRT) improve bone density?** The question we are asking is does it work? This is best answered by a RCT where patients are randomly given either HRT or a placebo. Patients in both groups are followed up for a period of time and specific outcomes are measured such as an improvement in bone density.
- **Does living under a power line increase your chance of developing cancer?** This is best answered by a case-control study where people with a particular disease or condition are identified and 'matched' with controls (patients who live in an area free from power lines). In this case, data would be collected on how exposed people have been to possible causes of cancer in the past.

**Assessing the quality of the study**

- Can we trust all published studies?
  It is important to remember that just because a research paper has been published in a journal it doesn't mean that we can trust it. Published studies may still have a number of flaws. This is why it is important that all studies used in our guidelines are critically appraised first.

- Who is the study about?
  We make sure that the study has included the groups of people we are interested in by asking the following questions:

- How were the people who took part in the study recruited?
  If you wanted to find out patients' preferences for a treatment, you could put an advert in the local paper. However, this would introduce selection bias as only the people who were motivated to take part and read papers would do so. It would be better to issue a questionnaire to every service user who visited their GP that day.

- Who was included and excluded in the study?
  Some trials in the UK exclude patients for example who already have an illness or who do not speak English. This can introduce selection bias. The results of a trial of medicine done in young healthy males may not apply to older females.

- Are the patients in study groups similar?
  To help limit bias, in all types of studies, (RCT, cohort study or a case-control study), the groups being compared should be as like one another as possible. This can include age, gender, stage of disease and social background as well as other features. Bias is anything which influences the conclusions of a study and affects how the groups in the study are compared.

- Was the assessment blind?-
  Blinding means that the people involved in the study do not know who is getting which treatment.

    - if patients knew, they might overestimate how much better they feel
    - if investigators knew, they might overestimate the effect of the medicine
    - did the study look at statistical questions first?

Understanding statistics is a challenge for most guideline group members. It may help to consider the following two areas when you look at the research:

1. The size of the sample – the trial should be big enough to have a high chance of detecting any statistically worthwhile effect and be sure that no benefit really exists if it is not shown in the trial.
2. How long the study will follow up the people who took part – a study must take place for a long enough period of time for the effect of the treatment to be reflected in the outcomes. If researchers were looking at the effects of a new painkiller used after operations, they may only need a follow up period of 48 hours. If they were looking at how nutritional supplements taken by preschool children affected their final height as adults, the researchers would need to follow up the people who took part for a number of decades.

Once we have asked these questions, we should be able to tell:

- what sort of study it was
- how many people were involved in the study
- where people came from
- what type of treatment was offered
- how long the follow up period was
- what methods were used to measure the outcomes of the study.

The Evidence and Information Scientists will rate each study as high quality (with a very low risk of bias), acceptable (with a low risk of bias) or low quality (with a high risk of bias). We can then decide if the paper can be used in the guideline or whether it is not good enough and we should reject it. The results of this assessment will decide how much evidence is relevant.

## What if someone has already written a guideline in the same area?

Sometimes good-quality guidelines will have already been written by other agencies. SIGN makes use of other guidelines produced elsewhere for use in NHSScotland. Guidelines that are produced using this approach will refer to these existing guidelines and will try not to repeat work that has already been done. However, before we refer to any existing guidelines, we will make sure they have been developed using acceptable methods. Sometimes existing guidelines may not be directly relevant to patients in Scotland or may have been developed using poor methods.

## Chapter 4: Making recommendations

So far, we've learned how to gather evidence. Next, we use clinical expertise and the values of people with lived experience to make practical recommendations. This makes sure that our recommendations are likely to be acceptable to people living with conditions and put into practice.

**What steps are involved to get from the evidence to recommendation?**

We call this stage 'considered judgement.' During this process, guideline development groups give a summary of all the evidence covered by each evidence table. This summary should cover the following:

- the amount and quality of the evidence, and whether it is consistent
- whether the findings of the studies carried out on a sample of people can be
- applied to the wider population
- whether the evidence can be applied directly to the people the guideline is for
- whether the treatments are effective and if there are any side effects or harms
- the resources needed to take on new treatments
- how acceptable the treatments are to people with lived experience
- how practical it would be for the NHS in Scotland to put the recommendation into practice.

Guideline development groups record the main points of their considered judgement. Once the groups have considered the issues, they summarise their view of the evidence and make the recommendation.

**Levels of evidence**

The 'level of evidence' tells you how likely it is that the conclusions of a research paper are true. It corresponds to the design of the study and how well it was done. Systematic reviews of randomised controlled trials (RCTs) and well-designed randomised controlled trials are the highest level, followed by observational studies such as cohort and case-control studies. Case studies and personal opinion are the lowest level.

Two Evidence and Information Scientists who appraise the quality of the study decide on the level of evidence depending on how well the study has been carried out.

**Making recommendations**

Our grading system places a lot of importance on the quality of the evidence that supports each recommendation. It emphasises that a recommendation should be based on the evidence as a whole and should not rely on a single study.

You will be involved in assessing whether the draft recommendations:

- are sensitively worded
- consider the treatments and outcomes that are important from the lived experience perspective
- take account of preferences of people with lived experience of conditions
- consider the needs of relevant groups of people (for example ethnic minorities).

**Grading recommendations**

The outcome of the decision making process is to make recommendations that are strong or weak based on the evidence. It will also take account of benefits and harms. We refer to weak recommendations as 'conditional.'

A strong recommendation is made where:

- the evidence is of high quality
- we are quite certain that the treatment will improve outcomes for people
- there are few downsides of the treatment
- treatment or therapy is highly accepted among people living with conditions.

A conditional recommendation is made where:

- there are weaknesses in the evidence
- there is some doubt that the treatment will produce the expected improvement in outcome for people
- we need to balance the benefits and harms of the therapy
- varying levels of acceptance among

Members of the guideline development group can also lower a recommendation from strong to conditional if:

- they do not think the findings of the study can be applied to the wider population
- the evidence cannot be directly applied to the people the guideline is aimed at, or
- they think the evidence is weaker than the study methods would suggest.

When the evidence is poor quality and the treatment has no downsides, a strong recommendation may also be made.

**Good practice points**

Guideline groups may want to emphasise a practical point which lacks evidence, like when a treatment is widely accepted but not been studied formally.

Points like this are shown as 'good practice points' and are marked with a tick. They should appear alongside an associated recommendation and cannot be standalone recommendations.

**Consensus statements**

When there's no good evidence, but the group feels strongly about a recommendation, they can make it, but it should be considered weak and based on low-quality evidence. They need supporting opinions from outside the group. If none exist, they should develop a consensus-based recommendation, clearly labelled as such in the guideline.

# Chapter 5: Consultation of guidelines

## What happens at consultation?

SIGN gathers feedback on a draft version of a new guideline from the wider health and social care community through:

- open consultation
- a national open meeting
- peer review.

When the guideline development group asks for input, they get helpful feedback and ideas about other evidence they could look at. This feedback might include different ways to understand the evidence and if it's realistic to follow the recommendations they're suggesting.

### Open consultation

The draft guideline is posted on the SIGN website for a month and widely publicised to relevant stakeholders. This includes:

- health and social care professionals
- third sector organisations
- other groups representing people with lived experience.

Comments are only accepted if the reviewer completes a declaration of interests form. You can read more about this in the volunteer handbook.

When there's a small change to published guidelines, we send the updated part directly to expert reviewers instead of putting it on the website.

Feedback is put into a consultation report for the group to consider.

### National open meetings

During the open consultation, SIGN might host a national meeting, either in person or online. At this meeting the group will talk about the draft recommendations in the guideline. National open meetings are open to the same groups as the open consultation. Particular efforts are made to ensure that all equality groups with a potential interest in the topic are invited to participate.

Delegates are encouraged to give feedback through discussion at the meeting, on social media and via the online consultation.

When we're updating existing guidelines or making new ones based on existing ones, there's no meeting. Instead, the guideline is put up for open feedback on the SIGN website for a month.

### Peer review

Before we publish any of our guidelines, health and social care professionals and academic experts review them independently. The draft is also sent to people who can provide us with comments from a lived experience perspective. This is known as the peer review process. We

ask peer reviewers to comment on the guideline, particularly:

- the way the guideline development group has interpreted the evidence
- whether the recommendations are clear and easy to understand
- whether the guideline is useful
- whether the guideline reflects views of people with lived experience.

We also ask the peer reviewers to suggest improvements to the guideline.

We invite third sector organisations and members of the Patient and Public Involvement Network to participate in the peer review process. We have written specific guidance for non-clinical peer reviewers and shared this on our website. It is important that we get the views of people with lived experience at this stage. If an organisation or individual has concerns about any of the recommendations in the draft guideline, they can let us know. People with lived experience and organisations representing them can also give feedback on the wording in the guidelines.

Although we write our guidelines for health and social care professionals, we aim to make them available to as many other people as possible. When people with lived experience and members of the public review the guidelines, we ask them to consider the following:

- overall use of jargon, and whether there are any terms they do not understand
- whether we can explain anything more clearly or more briefly
- the tone of the guideline
- if they can, suggest plain, non-technical wording to help healthcare professionals
- explain areas of the guideline to people living with conditions.

Each guideline contains a section called 'Provision of information.' This section is designed for professionals to use when they discuss a condition with people with lived experience. We particularly ask public representatives to comment on this section and make a note of the following:

- whether there is any jargon or any technical terms that we need to explain
- the tone of this section
- whether the wording deals with the condition sensitively
- whether the information is useful for people with lived experience.

Comments from peer reviewers will not be considered if a declaration of interests form has not been submitted.

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 dealt with. Once the guideline has been checked, we will publish it and make all relevant NHS staff and third sector organisations in Scotland aware of it. We publish the peer review report with the guideline.

## Chapter 6: Presentation of guidelines and plain language versions of guidelines

### Format for guidelines and plain language versions of guidelines

We aim to write our guidelines in clear language and to define any terms. Each guideline includes an introduction, which explains:

- Why the guideline is needed. This includes evidence of any differences in treatments or outcomes across Scotland.
- A short summary of the lived experience perspective.
- What the guideline aims to do, and who it is aimed at.

Each guideline has:

- a clear statement of the question or issue that has been considered
- a brief explanation of the treatment options available
- a summary of the conclusions drawn from the critical appraisal of the evidence
- the recommendations that the group has made from this evidence
- key recommendations that the guideline development group feels should be prioritised
- good practice points if the group feels it is important to give guidance on best practice based on their experience
- tools and activities to help put recommendations into practice
- recommendations for further research
- a section called 'Provision of information' which gives examples of information people may find helpful at key stages of care and treatment
- brief details of the search strategy and databases used.

Having a clear template for the final guideline can really help the development process. It lets the guideline group figure out early what information they need and how they'll organise it, making the process easier.

You can get guidelines for free on the SIGN website in PDFs. Some are also available as apps in the Right Decision Service (RDS). It's a digital service for Scotland with tools like websites and mobile apps. It helps you to make healthcare decisions quickly using the newest evidence, even when you're on the move.

### Different versions of guidelines

We produce:

- the full guideline, which has the guideline group's recommendations, how they were made and the evidence behind them
- a quick-reference guide, which is a summary of the main recommendations and other information
- a plain language version that explains the guideline's recommendations in a way that anyone can understand
- we make our guidelines as widely available as possible to make it easier for the recommendations to be put into practice.

**Plain language versions of guidelines**

We produce versions of the clinical guidelines for people with lived experience of conditions to:

- help them to understand what the latest evidence says about diagnosis, treatment and taking care of themselves
- encourage them to be fully involved in decisions about management of their condition
- point out any areas where things aren't clear.

Plain language versions of guidelines include:

- a brief summary of the condition
- a summary of tests, treatments and procedures we recommend
- how professionals can support people to help themselves
- further sources of information.

A small group of professionals and people with lived experience work on the plain language version. A public partner from Healthcare Improvement Scotland also joins this group. They give an honest user perspective to decide what goes into the simplified versions of guidelines. This helps us make sure our info is easy to access, friendly and clear for everyone.

The group picks out recommendations that can help folks be more involved in decision-making. They ask these questions to decide which ones are useful for people with firsthand experience and their families:

- can they help people understand their condition better?
- do they show people the interventions with the most proven benefits?
- do they suggest lifestyle changes and ways to manage the condition?
- do they point out treatments without evidence, and is it helpful for people to know this?

Plain language versions of guidelines are written directly to people with lived experience using a question and answer format. They're a translation of the guideline and only include the recommended procedures and interventions. Sometimes extra information is added to help people understand the recommendations better. These simple versions also point people to other sources of information like third sector organisations. People with lived experience on the group often know about helpful groups and can suggest them.

Consultation with a wider group of people ensures that the plain language version is accessible to everyone. The purpose of consultation is to ensure the plain language version is:

- readable
- relevant
- useful
- written in a sensitive way.

When asking for feedback, it's crucial to use a range of methods suited to fit the audience. For instance, when involving children and young people, a group chat might work better than asking for written feedback.

Plain language versions of guidelines are free on the SIGN website as PDFs. They might also come in other forms like apps in RDS, video animations or audio. We pick the format based on the topic and who it is for. We talk to people who have experience of the topic to choose the best format.

## Chapter 7: Putting recommendations into practice and updating guidelines

We want hospitals, general practices and NHS boards to follow our guidelines. The guidelines help staff to:

- make better decisions
- work well in teams
- learn more from evidence
- keep their practices consistent.

Local distribution coordinators within each NHS board ensure the promotion of our guidelines. We use the media to publicise guidelines if this is appropriate. Members of SIGN Council are also involved in promoting guidelines.

**How can third sector organisations help?**

Third sector organisations can promote guidelines and help other organisations follow them by:

- sharing guidelines on their website and in their communications
- including key points from guidelines in any materials they produce
- collaborating with NHS groups, professionals and community reps to implement guidelines locally.

**Barriers to getting guidelines into practice**

There are some barriers to getting guidelines into practice that SIGN has no control over. These include things like:

- budget constraints
- lack of equipment in hospitals
- people's perceptions and treatment preferences
- disadvantaged groups, for example homeless people.

These barriers contribute to inequalities in healthcare. For guideline recommendations to be put into practice, strategies need to be developed to address them. Each guideline development group signposts useful resources that will support implementation.

**When do you review the guidelines?**

Three years after a guideline has been published, we will look again at the evidence that was used to make the recommendations.

For guidelines up for review, we write a report. It covers new evidence, how well the old guideline worked, and any changes in the topic or treatments. We share this report with SIGN Council and others, and we listen to their feedback for the review.
When we review a guideline, we take a look at its original goals. We ask experts if these goals are still right, or if they need changing. Based on this discussion, we decide if a review is necessary. At this point, we have four options to choose from:

- confirm that the guideline is still valid
- carry out a full review of the guideline
- choose parts of the guideline to update
- confirm that the guideline has achieved its purpose or that it is no longer relevant and should be withdrawn.

If we get feedback on published guidelines or find new important evidence before a review, we'll share it with the guideline group. They'll either respond right away or think about whether the guideline needs a review. If the guideline needs an update before the review, we'll put this on our website.

**Living guidelines**

How often we update depends on how much new evidence comes out, typically once a year or every two years. Each update looks at parts of the guideline where there's new evidence. We search for new evidence based on the original questions. We only add new questions based on engagement with people with lived experience. If new evidence changes a recommendation or adds something new, we revise the guideline. The updates are then summarised in the published guideline.

**Withdrawing guidelines**

Sometimes guidelines may need to be withdrawn if they are outdated or no longer relevant. Guidelines will be withdrawn for the following reasons:

- a more recent or more comprehensive guideline is available
- there is evidence that the guideline has been fully complied with by NHSScotland, and has become accepted practice
- new treatments are available that make the guideline irrelevant.