

## Preparing a guideline topic proposal – information for patients, carers, voluntary organisations and members of the public

Before you start to prepare a topic proposal, you should consider who the other associated organisations are that can support the topic proposal. A proposal supported by a number of organisations helps to ensure a 'stronger voice' and can help to demonstrate the need for a guideline.

### What should be included in the topic proposal?

1. Details of all organisations supporting the proposal. The nature and purpose of each organisation should be briefly outlined, together with details of when organisations were established and website addresses.
2. Details of all individuals who have been involved in the preparation of the topic proposal. Each individual is required to complete a declaration of competing interests form. Please see SIGN's policy on declaration of interests which can help with this.
3. Details of how you have consulted with and gathered information about the experiences of patients and carers should be given. For example, information may have been gathered from focus groups, surveys, telephone help lines, online forums, published and unpublished literature.
4. Details of how the condition affects the day-to-day lives of people living with the condition.
  - A brief description of the condition.
  - People most likely affected by the condition.
  - Aspects of the condition that are most difficult to manage.
  - Challenges in managing the condition when patients also have other conditions.
  - Psychosocial impact of living with the condition.
  - Likely outcome of condition.
5. How do treatments available in NHSScotland help to manage the condition?
  - What are the main treatments used by patients?
  - How well do the treatments manage the condition?
  - What are the most important benefits to patients?
  - What are the effects of treatment on day-to-day living?
  - What are the side effects of treatment?
6. What are the potential improvements to quality of life and patient experience if a guideline is available?
  - Potential improvements to health outcome.
  - Level of improvements patients would like to see.
  - Emotional and psychological impact.

7. What kind of impact would a guideline have on a patient's family or carers?
  - Potential improvements in quality of life.
  - Emotional and psychological impact.
8. Any additional information you would like SIGN Council to consider. This section should be used for any additional information relevant to the topic proposal.

## **What not to include in the topic proposal**

### **1. Medical or scientific evidence**

As part of the guideline development process, Health and Information Scientists carry out a systematic review of the available evidence for different interventions. You do not have to provide this information.

### **2. Information from clinicians in relation to various interventions**

Clinicians will be invited to join the guideline development group. They will make recommendations for treatment based on the evidence. If no research has been done they will use their clinical experience and judgement to suggest best practice.

### **3. Information from news reports, blogs and opinion based reports**

This type of information can appeal to peoples' emotions. The information often appears to be professional and may quote well known experts working with a particular condition. However, it may not give a balanced view. Statistics are often provided to persuade people that the information they are reading is true but most of the time studies quoted are early findings based on small numbers of participants.

### **4. Language that is critical of SIGN's guideline development process**

You will feel very passionate about the condition you would like to see a guideline for. We have a well-defined process for producing guidelines and we are clear about what we can and can't do. It is best to highlight your key points as clearly as possible without detracting from them. This may be detrimental to your topic proposal.

**Full name of organisations supporting the proposal.**

**Who are the main contacts from organisations?**

**Please provide a brief description of each organisation. For each organisation, please include the following details:**

- Nature and purpose of the organisation
- Year the organisation was established
- Website address

**Please provide details of all individuals who have helped to prepare the topic proposal.**

**Please tell us about how you gathered information about the experiences of patients and carers to help inform the topic proposal.**

**How does the condition affect the day-to-day lives of people affected by the condition?**

**How well do treatments that are available in NHSScotland help to manage the condition? How easy is it to access treatments that are available?**

**Please tell us how you think a clinical guideline will benefit patients, carers and their families.**

**Is there any additional information you would like SIGN Council to consider?**