

Being a NICE patient expert

Overview

The National Institute for Health and Care Excellence (NICE) seeks evidence from patient experts during the appraisal of a medicine or new technology in order to provide as full an assessment of its clinical and cost effectiveness as possible. Patient experts are either patients themselves who may or may not have experience of the treatment, or representatives of a wider patient community who have an interest in the appraisal. In the majority of cases, NICE chooses two experts who have different perspectives on a therapy and who it believes will have an understanding of why it needs to be appraised by NICE.

Although the evidence given by patients and patient experts usually forms only a small part of the process, it is a vital opportunity to demonstrate the importance of positive NICE guidance and the impact it will have on patients. The meetings however can often be long and complicated, covering a lot of clinical detail that is not always easy for patients to follow. It is important that patients take the opportunity whenever possible to put across their view, with succinct and clear messages that will have a greater impact on the committee members.

Some useful tips relating to what is expected of a patient representative are highlighted below.

On the day: What to expect

The first appraisal committee meeting is split into two parts, and as a patient expert you will be expected to attend part one during which the committee aims to discuss as much as possible.

In the second part, the committee members will discuss the details of the appraisal and work towards producing their provisional recommendations. Confidential matters may be discussed (such as manufacturers confidential commercial or academic information). Or if you (patient experts) have personal or sensitive

matters that you do not wish to discuss in public, you may ask the Chair for discussion to take place in private, after which the committee will make their initial decision for consultation.

The meeting itself

- There will be approximately 35 people in attendance at the meeting.
- The committee meetings are held in public, (although in reality the public tends to be made of representatives from industry or pharmaceutical companies). However, if a carer or member of your family wishes to attend they can do so by registering on the NICE website.
- The meeting will last about half a day.
- The committee comprises people from varied backgrounds, such as doctors, pharmacists, health economists, statisticians and lay representatives.

The structure of the meeting

The meeting will start with a presentation given by members of the committee. This presentation will summarise some of the important issues that are likely to be discussed in the meeting. This will be followed by a full discussion in which committee members will ask you, and the other experts, questions.

Your role

- You will be asked to introduce yourself briefly.
- You will be asked questions about the effectiveness of the medicine or technology from a patient perspective and will have the chance to raise issues yourself.
- You will not be expected to make a presentation.
- You will not be involved in the decision making.



Remember: This is your chance to ensure that the views of the patients are heard. Your views can provide a new perspective on a topic, so it is important to have the confidence to raise issues if you think that they are important and not included (the Chair will tell you if they are not relevant and why).

Additionally, patients may measure improvements in health very differently from either the clinical trials or doctors; it is worth bringing up how you would measure an improvement if it is different.

What to do and what not to do

Do:

- **Concentrate** - The session can be very long and, in places, hard to follow, as the committee explores the clinical and cost-effectiveness of the medicine/technology. The Chair may address a question to you at any time, or wait until the very end of each part of the meeting.
- **Interrupt (within reason)** - At the start of the meeting you will be asked to introduce yourself along with the other experts but after this you may not be spoken to again for perhaps another hour. Interrupting the Chair or another member of the committee would not normally be advisable, but if you think a mistake has been made (particularly something that relates directly to the patient perspective), do let the Chair know that you would like to clarify something so that you can be brought into the discussion at the appropriate time.
- **Have a checklist** with you of the three most important messages you want to get across to the committee.
- **Refer any clinical questions** to the clinical experts.
- **Answer concisely** or the Chair may cut you off.
- **Be polite** and courteous throughout.

- **Align with other witnesses** to ensure that your messages have maximum impact.
- **Talk about the aspects of the issue that you are familiar with.** It is not advisable to wade into complex and controversial areas. The committee are looking to hear your views on the benefits or otherwise to patients of the treatment and nothing else.
- **Tell the patient story.** This will add weight to your argument. As a patient expert, your role is to bring life to the medicine/technology and provide a contrast to the clinical and scientific evidence given by others. However, again, it is important to be concise and to make a story relevant.
- **Reply directly** to a questioner – not through the Chair.
- **Sit forward and speak clearly.** Remember to use the microphone in front of you so that all members of the committee can hear you.

Don't:

- **Lose your temper!**
- **Engage in an argument** with a questioner or another witness.
- **Talk to another witness** while the committee is in session.
- **Be afraid to repeat** a point you may have already made (particularly if it's a good one). At the end of the session, the Chair is likely to ask the patient experts if they have anything to add. When an open question like this is put to you, it can be a good opportunity to restate your key points in a concise closing statement.

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