

## ***Public Involvement Programme***

### **Nominating patient experts: a factsheet for patient and carer organisations**

#### **Who is this for?**

It is intended for patient/carer organisations taking part as consultees in the National Institute for Health and Care Excellence (NICE) technology appraisals. Patient and carer organisations invited to participate in an appraisal are also asked to nominate patient experts to represent the patient's view (as an individual) at the first meeting of the Technology Appraisal Committee. The Committee meeting will be held in either Central London or Central Manchester. NICE will reimburse travel costs.

Through patient expert nominations, you can ensure that the interests of patients and carers have a voice at the Committee meeting. This document has been written to support your organisation in putting forward a successful patient expert nomination. The accompanying document entitled 'Hints and tips when preparing to be a patient expert' is written for the patient experts and sets out in more detail what the role of patient expert involves.

#### **What is a patient expert?**

The role of the patient expert is to participate in the discussions and answer the Appraisal Committee's questions, relating to patients' experience of the therapies under appraisal and the condition that they treat. They attend as individuals rather than representatives of their nominating organisation.

Although patient experts do not necessarily have to be patients or carers themselves, they need to be an expert on patient issues. Patient experts are joined at the Committee meeting by Clinical Experts who will represent professional experience.

Technology Appraisals Committees are open to the public as part of NICE's commitment to openness and transparency. There is potential for up to 20 people to observe the meeting, including interested members of the public, members of the press and people from other stakeholder organisations such as the pharmaceutical industry. It will be useful for you to consider this when making your nominations. Additionally, you may consider attending yourself, particularly to support any patient experts that were nominated by your organisation.

Typically, the meeting will be held in 2 parts – with the first part open to the public and the second part closed, to protect sensitive information. If a patient expert is asked about anything which they do not wish to discuss in public, they may ask the Chair for

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discussion to take place in private. A decision not to hold the second part of the meeting will be taken by the Chair when there is no confidential or personal information for consideration. Patient experts are entitled to ask the Chair (before the meeting) for any sensitive evidence they wish to declare to be heard in private.

Patient and carer organisations are encouraged to nominate as many patient experts as possible to ensure sufficient representation of patient experts at the Committee. However, it is not guaranteed that your nominations will be selected as nominations by other organisations will also be taken into account when selecting patient experts. We welcome a wide range of patient views at the meeting, and unless no nominations have been made, at least 1 patient expert will be appointed. We aim to invite different types of patient experts where possible.

We recommend that you nominate:

1. One patient expert with a broad knowledge of the condition, current treatments, new treatment and outcomes that are important to patients.
2. One patient expert with personal experience of the condition, and where possible the treatment in question.

### **How do patient experts contribute?**

Patient experts' contribution to Technology Appraisals has 3 main components:

1. Before the meeting, all experts (that is, both patient and clinical) are asked to write a short personal statement template, which sets out their experience and views on the condition or therapies under appraisal. However, if the nominating organisation has submitted a statement (on behalf of the organisation), then the expert can choose to agree with that instead.
2. At the meeting, Patient experts are asked questions relating to their experience and may participate in the discussions.
3. After the meeting, Patient experts are encouraged to submit written comments on the Appraisal Consultation Document, which is the first draft recommendation.

Before the meeting, it is useful for patient experts to think about their experience and views on the condition or therapies under appraisal. Additionally, it is a good idea to have a basic understanding of why NICE appraises new technology and how the appraisal process works. We recommend that they read 'hints and tips for patient experts.'

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### **Who should you nominate?**

When thinking about who to nominate as a patient expert, you might consider the following:

- Patients who have experience of the condition being appraised.
- Preferably patient experts who have recent experience of the specific therapy being appraised. Not all therapies are used in clinical practice in the UK; therefore, experience of the specific therapy that is being appraised is not always possible.
- Patient experts can either have personal experience of the condition, and where possible the treatment in question or a broad knowledge of the condition, current treatments, new treatment and outcomes that are important to patients.
- Unless they are themselves patients, try to avoid nominating clinicians as patient experts. Professional views are already represented in the appraisals process and the Committee is also keen to hear from patients themselves, or from people who can talk from a patient's perspective.
- Try to identify nominees who represent different subgroups in the patient population and have different experiences and expectations (based on, for example, age, ethnic background, sex and good/bad experience of therapy).
- Evidence from patient experts tends to have the highest impact if it represents a balanced view, that is, it gives emphasis to both positive and negative effects of a given therapy.
- If possible, try to nominate someone who is used to attending meetings, is comfortable with public speaking and would feel able to get their point across, particularly with the meeting being held in public.
- It is an advantage if your nominees are knowledgeable about previous input into the appraisal from your organisation. Some organisations choose to involve the prospective patient expert in compiling their written statement of evidence.
- Patient expert nominations need to be made with the full consent of nominees. Patient expert nominees also need to be aware that their name and contribution will be included in documentation produced for the appraisal.

### **Equalities**

At NICE, we are committed to promoting equality and eliminating unlawful discrimination in our activities and guidance we produce.

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### **Checklist**

#### **Patient/carers organisations need to nominate:**

- ✓ people who have consented to their nomination
- ✓ people representing different patient perspectives (if possible)
- ✓ people who are able to keep the patient perspective to the forefront rather than become focused on clinical or economic discussions
- ✓ people who are able to give different sides of the argument
- ✓ people who have an understanding of the appraisal process
- ✓ people who are confident when speaking in front of large groups and members of the public
- ✓ people with experience of attending high-level meetings or committees
- ✓ people who will be committed to preparing for the role by doing some reading before the meeting

The nomination should then be sent by completing an official nomination form which you will have received from the Appraisals Team as part of the 'Invitation to Submit' mailing. Half the form is completed by your organisation, and half by the nominee. If you need a replacement form, please ask.

If you have any questions, please contact:

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