

## **Patient/Carer Organisation Statement Template**

Thank you for agreeing to give us your views on the technology and the way it should be used in the NHS.

Patients and patient advocates can provide a unique perspective on the technology, which is not typically available from the published literature.

To help you give your views, we have provided a template. The questions are there as prompts to guide you. You do not have to answer every question. Please do not exceed the 8-page limit.

### **About you**

████████████████████

**Name of your organisation:**

**Atrial Fibrillation Association**

**Are you (tick all that apply):**

- **a patient with the condition for which NICE is considering this technology? x**
- a carer of a patient with the condition for which NICE is considering this technology?
- an employee of a patient organisation that represents patients with the condition for which NICE is considering the technology? If so, give your position in the organisation where appropriate (e.g. policy officer, trustee, member, etc)
- other? (please specify)

**What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition?**

### **1. Advantages**

(a) Please list the specific aspect(s) of the condition that you expect the technology to help with. For each aspect you list please describe, if possible, what difference you expect the technology to make.

**This technology would appear to have the advantages of some of the other drugs without many of the side effects**

**~It does not have the toxic effects that some previous drugs have,so therefore the treatment could be available to more people.**

**I expect this technology to improve the quality of life to many patients in AF**

(b) Please list any short-term and/or long-term benefits that patients expect to gain from using the technology. These might include the effect of the technology on:

- the course and/or outcome of the condition
- physical symptoms
- pain
- level of disability
- mental health
- quality of life (lifestyle, work, social functioning etc.)
- other quality of life issues not listed above
- other people (for example family, friends, employers)
- other issues not listed above.

I

**It would appear that this technology will alleviate many of the symptoms of AF, like palpitations and therefore the breathlessness, and feeling lightheaded and many other symptoms that AF can present with.**

**By controlling the symptoms it will generally improve the quality of life and therefore this will have an effect on anybody involved with the person taking the drug**

What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition? (continued)

## **2. Disadvantages**

Please list any problems with or concerns you have about the technology. Disadvantages might include:

- aspects of the condition that the technology cannot help with or might make worse.
- difficulties in taking or using the technology
- side effects (please describe which side effects patients might be willing to accept or tolerate and which would be difficult to accept or tolerate)
- impact on others (for example family, friends, employers)
- financial impact on the patient and/or their family (for example cost of travel needed to access the technology, or the cost of paying a carer).

**some people are still going to be unable to take the drug because of adverse reactions but this happens to everything, it would be hoped with this treatment that it will be less others**

**~it can be prescribed by the gp and therefore will involve less visits to the hospital**

3. Are there differences in opinion between patients about the usefulness or otherwise of this technology? If so, please describe them.

4. Are there any groups of patients who might benefit **more** from the technology than others? Are there any groups of patients who might benefit **less** from the technology than others?

**There are some groups of patients that because of underlying conditions will be unable to take this drug**

### **Comparing the technology with alternative available treatments or technologies**

NICE is interested in your views on how the technology compares with with existing treatments for this condition in the UK.

(i) Please list any current standard practice (alternatives if any) used in the UK.

**This compares favourable with Amioderone as it does not appear to have the side effects**

(ii) If you think that the new technology has any **advantages** for patients over other current standard practice, please describe them. Advantages might include:

- improvement in the condition overall
- improvement in certain aspects of the condition
  - ease of use (for example tablets rather than injection)
- where the technology has to be used (for example at home rather than in hospital)
  - side effects (please describe nature and number of problems, frequency, duration, severity etc.)

The main advantages that I see is the lack of side effects that previous treatments had

(iii) If you think that the new technology has any **disadvantages** for patients compared with current standard practice, please describe them. Disadvantages might include:

- worsening of the condition overall

- worsening of specific aspects of the condition
- difficulty in use (for example injection rather than tablets)
- where the technology has to be used (for example in hospital rather than at home)
- side effects (for example nature or number of problems, how often, for how long, how severe).

### **I cannot see any disadvantages at present**

Research evidence on patient or carer views of the technology

If you are familiar with the evidence base for the technology, please comment on whether patients' experience of using the technology as part of their routine NHS care reflects that observed under clinical trial conditions.

Are there any adverse effects that were not apparent in the clinical trials but have come to light since, during routine NHS care?

Are you aware of any research carried out on patient or carer views of the condition or existing treatments that is relevant to an appraisal of this technology? If yes, please provide references to the relevant studies.

### **Availability of this technology to patients in the NHS**

What key differences, if any, would it make to patients and/or carers if this technology was made available on the NHS?

**More patients will be able to take this treatment.  
It could involve less frequent visits to the hospital**

What implications would it have for patients and/or carers if the technology was **not** made available to patients on the NHS?

**If this was not made available to the patients on the NHS it would mean that more people would still suffer from AF because they were unable to take the alternative medications**

Are there groups of patients that have difficulties using the technology?

**There are always some groups of patients that cannot use new technologies, as I understand it patients with some existing heart complaints may be unable to take this medication**

### **Other Issues**

Please include here any other issues you would like the Appraisal Committee to consider when appraising this technology.