

## Appendix D – Patient/carer expert statement template

**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**

Your name: JO JEROME

**Name of your organisation:**

ATRIAL FIBRILLATION ASSOCIATION  
(AFA)

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

- a patient with the condition for which NICE is considering this technology?
- 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)

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**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.

- Reduction of symptoms for a patient with Atrial flutter or Atrial fibrillation.
- Treatment option with fewer side effects than current options available.
- I expect both points listed above will considerably improve the quality of life a patient can enjoy and the work / social activities they will be able to

(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.

• maintaining a quality of life which will include:

- feeling healthier
  - fewer symptoms of AF/flutter } Both resulting in
  - fewer side effects
- fewer visits to medical centres.

- able to continue / return to work
- able to continue a life style which is not dependant of help due to incapacity from AF/flutter.

- interact in family / social life - return this will benefit mental health.

- continue healthier lifestyle.
- remain or return to being a person not a patient, therefore giving to society and being part of it.

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**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).

- Not suitable for all AF/ flutter patients.  
 - from test results, may not be as effective at reducing AF than amiodarone BUT much less harmful or far fewer side effects.

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

None that I am aware of.

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?

- Patients with other heart problems, in particular those with significant heart failure.
- There is also no information currently available for patients who may also be pregnant or breast feeding.

National Institute for Health and Clinical Excellence

Patient/carer organisation statement template

Single Technology Appraisal of Atrial fibrillation and atrial flutter - Dronedaron

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**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.

Other drug options include:  
amiodarone (very toxic) flecainide

(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.)

All antiarrhythmic drugs seem to have some side affects / not be suitable or effective in all sufferers / have a limited "life" - in that too often they each eventually seem to become less affective against AF/flutter symptoms. This will be a new drug in the options and extend symptom reduced time.

(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).

None that I am aware of.

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**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.

Unknown as trials were not in UK - to my knowledge.

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

None to my knowledge.

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.

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**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?

Atrial fibrillation and Atrial flutter can be debilitating medical conditions which can cause misery, ill health and incapacity to - work/ be an active part of a family etc. Currently, choices are limited, and may bring side effects. A medication which will reduce symptoms and so improve a person's quality of life and also reduce the need to keep returning to a doctor for help - reducing costs for the patient and for the NHS, would be welcomed.

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

Remain with limited choice and choice not suitable for all and each with possible side effects.

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

None to my knowledge

**Other Issues**

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

How it will be prescribed (by whom), so how a patient will be assessed to be prescribed it.