

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: [REDACTED]

Name of your organisation: Atrial Fibrillation Association

Are you (tick all that apply) (highlighted in green):

- 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)

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.

Improved management of the symptoms of AF in some AF patients. The symptoms of AF can be very distressing for patients and their carers and can have a significant negative impact on their quality of life. Symptomatic patients can suffer from severe palpitations which can last from a few minutes to several days, some patients experience breathlessness which can be very distressing and can often cause panic in the patient who may think they are having a heart attack. It is expected that the technology could help to manage these symptoms of AF recurrence in suitable patients.

Current anti-arrhythmic treatment options are limited due to side effects for example patients can experience severe thyroid toxicities or pulmonary fibrosis with amiodarone, others may experience photosensitivity, all of which mean that many patients cannot tolerate long term treatment with amiodarone. Other anti-arrhythmic agents can carry some risk of pro-arrhythmia's which can have devastating effects on patients and their families. It is expected that the technology will enable patients to experience relief from their AF symptoms without severe side effects which may mean that patients can remain on treatment long term.

It is expected to provide an alternative to the current anti-arrhythmic medication available. Patients and carers will welcome an alternative treatment option which may be safer than those currently available.

The technology has been shown to reduce stroke risk in a clinical trial. Patients with AF are five times more likely to suffer a stroke than those without and a technology that can reduce this risk is welcomed by patients and their carers.

(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.

As above plus:

Improved quality of life through reduction of AF symptoms.

Improved emotional stability due to AF management.

Reduction of debilitating symptoms AF patients may experience.

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).

The technology may not be suitable for all AF patients.

May have a cost implication and therefore may not be easily accessed by all patients.

Unknown long term side effects.

Unsure how long effectiveness may last.

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

Many hope this is an ultimate answer to reducing AF.

Many AF patients may not be able to access this treatment or be suitable for it and so be extremely despondent.

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?

Unknown as not currently available for use.

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.

Current commonly used anti-arrhythmic agents used include sotalol, flecainide and amiodarone.

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

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- 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.)

Current anti-arrhythmic treatment options are limited due to side effects for example patients can experience severe thyroid toxicities or pulmonary fibrosis with amiodarone, others may experience photosensitivity, all of which mean that many patients cannot tolerate long term treatment with amiodarone. Other anti-arrhythmic agents can carry a risk of pro-arrhythmia which can have devastating effects on patients and their families. It is expected that the technology will enable patients to experience relief from their AF symptoms without severe side effects which may mean that patients can remain on treatment long term.

(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).

Patients who are unable to access the technology or who do not know how to access it will be at a disadvantage.

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.

Not known. Technology not yet available in UK.

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

No, technology not yet available in UK.

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.

Not aware of any although patients have indicated that they will welcome a new treatment for AF.

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?

Improved management of the symptoms of AF in some AF patients. The symptoms of AF can be very distressing for patients and their carers and can have a significant negative impact on their quality of life. Symptomatic patients can suffer from severe palpitations which can last from a few minutes to several days, some patients experience breathlessness which can be very distressing and can often cause panic in the patient who may think they are having a heart attack. It is expected that the technology could help to manage these symptoms of AF recurrence in suitable patients.

Current anti-arrhythmic treatment options are limited due to side effects for example patients can experience severe thyroid toxicities or pulmonary fibrosis with amiodarone, others may experience photosensitivity, all of which mean that many patients cannot tolerate long term treatment with amiodarone. Other anti-arrhythmic agents can carry some risk of pro-arrhythmia's which can have devastating effects on patients and their families. It is expected that the technology will enable patients to experience relief from their AF symptoms without severe side effects which may mean that patients can remain on treatment long term.

It is expected to provide an alternative to the current anti-arrhythmic medication available. Patients and carers will welcome an alternative treatment option which may be safer than those currently available.

The technology has been shown to reduce stroke risk in a clinical trial. Patients with AF are five times more likely to suffer a stroke than those without and a technology that can reduce this risk is welcomed by patients and their carers.

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

Reduce options available.
Limit a patient's options.
Cause disappointment in many patients who are eagerly awaiting the introduction of a new treatment option.

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

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Yes, those not suitable to take this drug.

Other Issues

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

How will patients access the drug?

Who will prescribe it?

Costs involved.