

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: Annya Stephens-Boal

Name of your organisation: Lifeblood : The Thrombosis Charity

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) – I am Lifeblood's Executive Officer
- 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.

Most importantly the drug is given orally.

Currently thromboprophylaxis is given by subcutaneous injection which is painful.

Often the patients are unable to self-inject when they return home meaning that a District Nurse will have to visit to administer treatment which is expensive too!

The data available suggests this drug is also safer than the currently used low molecular weight heparin as there are no major side effects such as heparin induced thrombocytopenic thrombosis (HITT).

Lastly it also appears to be more efficacious with a similar risk of side effects such as bleeding

(b) Please list any short-term and/or long-term benefits that patients expect to gain from using the technology.

There is benefit in terms of pain reduction as this drug removes the need to self inject.

There is also a benefit to patient's mental health in terms of stress reduction amongst those people with needle phobia or other difficulties with self-injection.

2. Disadvantages

Please list any problems with or concerns you have about the technology.

There are no perceived major disadvantages associated with this technology.

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

No

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 needle phobia will benefit more from this technology as it removes the need for injections.

Comparing the technology with alternative available treatments or technologies

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

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

Current standard practice used in the UK are low molecular weight heparin and Fondaparinux.

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

We consider there will be improvement in the condition overall as this technology appears to be more efficacious.

There will be definite improvement in terms of ease of use as this technology is orally administered as opposed to injected.

This technology is advantageous for use at home. Thromboprophylaxis is given for 35 days after hip replacement and 10-12 days after knee replacement so these patients will be taking tablets at home instead of self injecting or having a District Nurse administer injections for them.

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

None

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.

No. Very few Centres are using the drug as yet, so we cannot comment on this.

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

Not as far as we know

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.

No

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?

This technology would make key differences to both patients and carers in terms of drug administration. As this drug is administered orally it removes the need for the patient or carer to inject their drug therapy for up to 35 days following surgery.

It would be particularly useful to more elderly patients who would find it much easier to take a pill every day rather than self-inject or have someone come in every day to do it for them.

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

If this technology was not made available to patients on the NHS, it would take away their freedom of choice and remove accessibility to an efficacious therapy with fewer side-effects and disadvantages to current therapies.

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

No. In fact in some cases it could prove quite the opposite.

Patient/carer organisation statement template

Other Issues

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

None