

## **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:** Arthritis Care

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

- 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)

**Policy Research Manager**

**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.

Where high levels of uric acid are found to be present, febuxostat could be useful in preventing the onset of gout. In people who have already experienced gout, febuxostat will reduce the likelihood and frequency of attacks. It also reduces the likelihood of developing chronic gout, which, if the condition is left untreated, can develop after several years of intermittent flare-ups.

(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.

In lowering the levels of uric acid in the blood febuxostat reduces the likelihood of gout flare-ups. Gout is an extremely painful condition and people frequently report being unable to bear any weight on affected joints. This can lead to short-term mobility difficulties for the duration of the flare-up, sometimes requiring wheelchair use and affecting social activities and independence. The pain is also known to cause sleeplessness, affecting emotional and mental wellbeing. The sudden onset of extreme pain after clear periods of many months or even years can make coping difficult; treatment using febuxostat will reduce the incidence of sudden flare-ups and make the condition more manageable. In addition, in acting as prophylaxis against chronic gout, febuxostat will improve quality of life in the long term.

**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).

As with allopurinol, studies show a possible increased chance of developing further attacks of gout immediately after treatment begins. However, with sufficient painkillers the effects could be minimised.

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?

The following groups would all benefit from the technology:

Gout patients who are currently under treatment and are experiencing hyperuricaemia.

Current patients who are at risk of renal failure.

People who experience adverse reactions to allopurinol or whose condition does not respond to it.

People with recurrent gout; as a method of preventing flare-ups and reducing their likelihood of developing chronic gout.

**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.

Allipucinal?

(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.)

With the exception of allopurinol, the current available treatments for gout treat the symptoms rather than the cause. NSAIDs and corticosteroids provide temporary relief from swelling and consequent pain. Colchicine has a similar purpose but is known to have adverse effects and is not well tolerated.

Febuxostat would provide long term protection from flare-ups of gout and could be a useful alternative for people who cannot tolerate allupurinol. One study suggests that allopurinol significantly increases adverse events compared with febuxostat.

[ Becker MA, Schumacher, HR Jr, Wortmann RL, et al. Febuxostat compared with allopurinol in patients with hyperuricemia and gout.]

(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).

**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?

At the moment, there is only one comparable treatment for hyperuricaemia available: allopurinol, meaning people have restricted choice. It is extremely important that people with hyperuricaemia have the widest possible access to effective treatments. In the event of adverse reactions to allopurinol or where it is not tolerated or ineffective, febuxostat would provide a vital alternative. Its availability on the NHS would therefore be of benefit to the estimated 2% - 4% of patients who cannot tolerate allopurinol.

In addition, the reduced incidence of gout flare-ups effected by febuxostat treatment would reduce the need to access NHS services for painkillers and anti-inflammatory drugs, easing the pressure on NHS staff time as well as being more convenient and comfortable to the person with gout. Those treated with feboxustat would be at less risk of developing chronic gout, significantly improving their long-term health.

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

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

### **Other Issues**

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