

## 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: **The Psoriasis Association**

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)

**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.

- *Adalimumab is indicated for the treatment of moderate to severe plaque psoriasis for which other treatments have failed. Patients are looking for a rapid reduction in scaling, redness and soreness as well as relief from intense itch.*

(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.
- *Relieving the physical symptoms of moderate to severe psoriasis should lead to improved sleep patterns and improved general health.*
  - *Psoriasis can have a profound social and psychological impact and relief from the worst symptoms should lead to improvements in a patient's mental health and their ability to cope on a day to day basis. This in turn will help families and carers cope with the impact of the condition.*
  - *For patients, whose psoriasis is so severe they are unable to work, any relief from the symptoms may help them return to work and not be reliant on benefits.*

**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).
- *Adalimumab is a relatively new treatment and there is, as yet, no long term data on efficacy or side effects.*
  - *Administering the treatment by self injection may not suit all patients.*
  - *People need to be made fully aware of possible side effects in order to make their own informed decision about whether or not to take the treatment.*

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?

- *Adalimumab is clearly indicated for the treatment of moderate to severe chronic plaque psoriasis – it will not help those with mild to moderate disease or people with less common forms of psoriasis such as pustular psoriasis on hands and feet although these may still have a profound impact on everyday life.*

### 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.

- *The majority of people with psoriasis will be using emollients and topical treatments prescribed by their GP. These can be smelly and messy and can be time consuming as well as difficult to apply to some parts of the body.*
- *For people with more severe psoriasis there is UV therapy or a range of systemic drugs. UV treatment requires frequent hospital visits over a period of weeks – difficult to achieve if you work or have caring responsibilities.*
- *Inpatient treatment for severe psoriasis involves a lengthy stay in hospital and can be impossible for some people.*

(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.)
- *Reduction in the need for other topical or systemic treatments.*
  - *Self injection may make a patient feel more in control of their own medication.*

(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).
- *Some patients may find self injection difficult.*

**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?

- *Adalimumab increases the number of biologic treatments available to those people who have the most difficult and intractable psoriasis.*

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

*Adalimumab is one of a range of new drugs that offer real hope of managing a difficult condition. To deny patients access to the full range of new and effective drugs would be frustrating for patients and their families. It would deny them the opportunity to lead a normal, economically and socially active life free of the worst symptoms of psoriasis.*

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

*Patients with psoriatic arthritis that limits fine motor movement may find self injection difficult.*

**Other Issues**

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

*The Association feels that Adalimumab should be available on the basis of clinical need and that there should be careful monitoring to ensure that it is used properly and effectively and there should be careful monitoring of side effects.*