

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

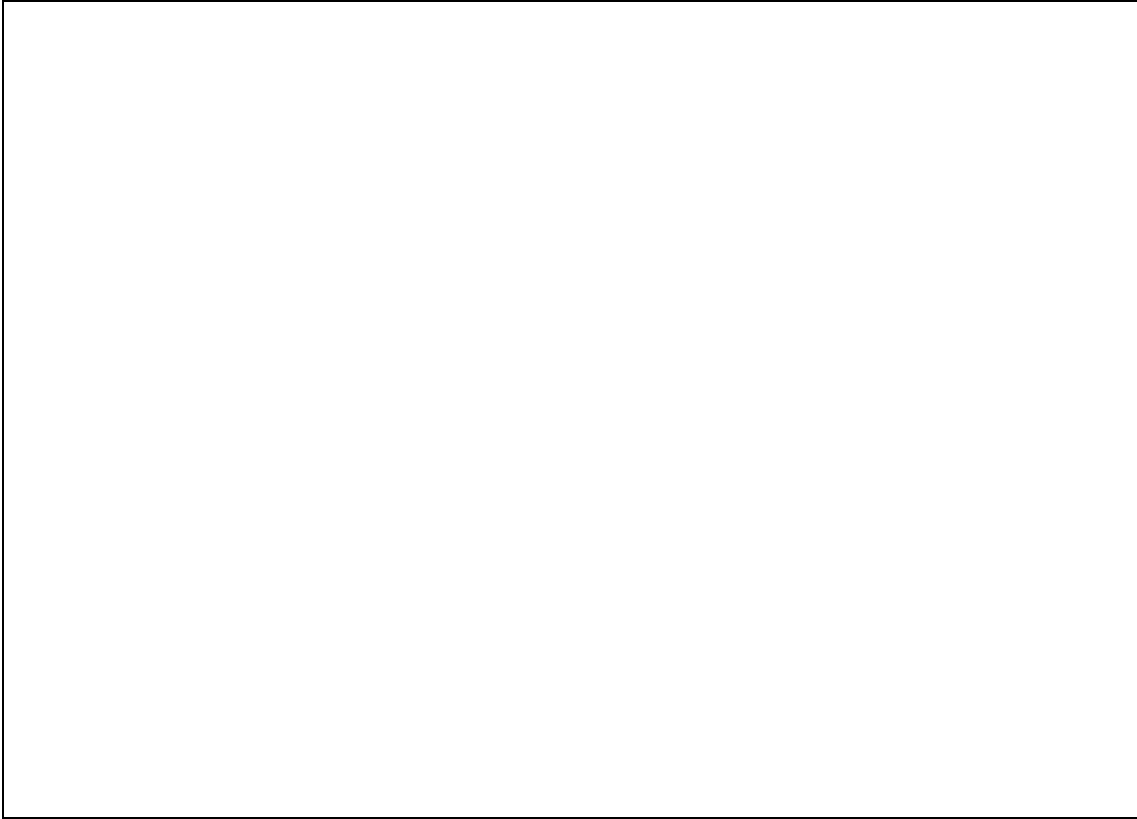
Your name: [REDACTED]

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) Chief Executive
- 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.

Ustekinumab is not yet licensed but expected indications are for people with moderate to severe psoriasis for whom all other treatments have failed or are contra – indicated. It should offer relief from the problems of itching, redness, soreness, pain and scaling of widespread severe psoriasis.

(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.

This drug is targeted at people with really difficult psoriasis for whom all other treatments have failed. Living with severe psoriasis can be frustrating, painful, tedious and have a profound impact on day to day life.

Any relief from the difficult symptoms of psoriasis should lead to an improvement in general health. Improvement in the physical symptoms of the condition should lead to improvements in a patient's mental health, their ability to cope on a day to day basis and help families cope.

For people whose psoriasis is so severe it prevents them from working an improvement in the physical symptoms may help them back to work.

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).

Ustekinumab is a very new treatment so there is little long term data on efficacy or side effects.

Some patients might find self injection difficult.

People need to be fully aware and informed of the potential side effects particularly the risks of infections.

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?

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.
- 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 to apply as well as being difficult to apply to some parts of the body.
 - For people with more severe psoriasis there is UV treatment or a range of systemic drugs. UV treatment requires frequent hospital visits over a period of weeks – difficult to achieve if you are working. The systemic drugs have potentially difficult side effects and require ongoing monitoring.
 - Inpatient treatment for severe psoriasis can involve admission for 2 weeks or more and can be impossible for some people e.g. no-one at home to look after children.
- (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.)

Ustekinumab is administered by self injection on a monthly basis offering the potential to be free of daily treatment regimes. However, it is likely that emollients and moisturisers will be needed on a daily basis.

- (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).

The increased risk of infections may be a problem for some people.

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?

Ustekinumab represents another treatment for people with psoriasis and, with a different mode of action from other biological drugs, increases the range of treatment options available for patients with difficult to treat psoriasis and their clinician.

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

Ustekinumab is one of a range of new drugs that offer hope of managing a difficult condition and to deny patients access to new, effective drugs would be frustrating for patients and 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?

Other Issues

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