

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:

██████████

Name of your organisation:

Psoriasis and Psoriatic Arthritis Alliance

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.

To offer further treatment choice when other treatments fail to provide improvement. Also could add to treatment options when making decision on which element of the condition is likely to benefit most, if the patient also has psoriatic arthritis.

(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.

The use of effective treatments can improve the short and long term impact psoriasis has on daily lives, by providing long-term clearance without the use of inconvenient or messy delivery methods. These include topical application or out-patient visits for courses of treatment such as PUVA or other light therapy.

Concordance with a therapy that is less time consuming and isn't a constant reminder of disease or that impacts significantly on daily life, will make patients feel a sense of freedom from the daily drudge of chronic disease management. This also reduces the impact on other members of the family and allows people to feel less stigmatised by a disfiguring disease. The burden, guilt and impact on spouses, children and other family members that someone with severe psoriasis feels can be enormous. Clear 'normal' skin will give people with psoriasis more self confidence and provide a better quality of life. This may also include better prospects for employment and make the ability to attend work easier

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 problem with any treatment is the sense of the unknown, lack of knowledge regarding whether a treatment will work before commencement, which may cause a patient to be deflated quickly if significant improvement or no improvement is seen. The psychological impact of returning disease or failure to respond also provides a sense of hopelessness or no where to turn, this will also impact on family, friends and employment, hence the need for choice and options that can be tried.

New treatments although rigorously testing do not have a long-term safety record. Side-effects that have not been seen in trials may develop in 'real patients'. People need to be made aware of this and long term safety data needs to be collected. With these potential unknown elements, careful consideration of the benefits and risk should be discussed with the patient, so an informed choice can be made. Patients should fully understand that these treatments are powerful and that is also their responsibility to fully understand the commitment they are making when commencing treatment.

Some patients may have difficulty with the process of subcutaneous injection or find the concept difficult to grasp, the use and storage may also cause issues that needs to be considered and the impact that this may will have on domestic life.

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?

More severe patients must be considered as an option for this treatment, or in less severe patient where all other treatment has failed and disease in having a significant impact of quality of life issues.

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.

Topical applications, including Vitamin D analogues, mild to potent steroids, light therapy, oral methotrexate, other biological therapies

(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.)

Until long-term safety is determined, it provides further choice when first and second line treatment fail or the patient no longer responds or is on the severe end of the psoriasis spectrum.

(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 long-term safety data and impact that the treatment will have on an individual as they get older needs to be established.

The options that are left if a patient fails to respond and the psychological impact that a patient may feel knowing that all options have been tried. Any unwanted side-effects that are discovered that preclude other treatments. Impact on co-morbidities that may not have been present in trial patients.

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?

The technology will add choice and options to patients, particularly if other similar treatments fail or the patient is not happy with side-effects of delivery methods.

If a patient also has psoriatic arthritis, this technology may provide an alternate choice or further option in the management of both conditions.

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

There are other similar treatments which are available. The patient's and physician's treatment options are limited to those available, which may not work in all patients, if there are not alternates or choice, patients may be left with no appropriate treatment. The option to try a treatment that may not be seen as first choice but could be effective on an individual basis, will have significant impact on an individual's outcome and disease management.

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

Those unable to self inject or who have phobias relating to the use of injections.
Those who have limited mobility in their hands, common problem for people with psoriatic arthritis

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Other Issues

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

The impact that the treatment will have on psoriatic arthritis and other co-morbidities.

Availability based on individual choice and clinical need and not solely on cost
effective analysis of a 'broad brush' majority effectiveness