

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: ANDREW LANGFORD

Name of your organisation: SKIN CARE CAMPAIGN

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.

Currently there is very little successful treatment available for those with chronic hand eczema and alitretinoin offers an opportunity to address this gap and provide a treatment that could give back the use of their hands to many who have suffered for a long time

We specifically expect and have seen in patients who have already received alitretinoin significant improvement in the painful dry skin that so many are affected by -. With successful use of alitretinoin we expect many to have near normal skin on their hands. Alitretinoin has approval and is used successfully in Scotland, Germany, France, Denmark, and Finland

Hand eczema has been shown to be a major cause of prolonged sick-leave and job loss: 20% of patients reported taking sick-leave and 23% reported they had lost their job at least once in a 12 month period due to their hand eczema. (BJD 2005 152(1):93-98) Effective treatment of severe hand eczema by alitretinoin will patients to return to employment and should reduce more temporary work absenteeism due to hospital attendance or sick leave. These effects may lead to important benefits to the wider economy.

(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

It is hoped that continued treatment will alleviate the hand eczema all together

- physical symptoms

The skin on patient's hands will return to normal and not be dry scaly or have any eczema

- pain

By clearing up the eczema each patient should become pain free

- level of disability

Currently many are disabled by not being able to use their painful, sore hands – it is hope that people will regain the use and no longer be disabled.

Examples of the effect of successful treatment with alitretinoin include:

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- Return to work for many who have previously been unable to work because of the pain, discomfort and restricted movement of their hands
- People being able to hold pens, cutlery, scissors etc again
- People being able to pick up their children / grandchildren for the first time

- mental health

Hand eczema is extremely debilitating and leads to depression and feelings of being useless – treatment would alleviate these.

- quality of life (lifestyle, work, social functioning etc.)

Successful treatment would ensure people holistic health would improve significantly. Many would no longer have to live on benefits and could return to work.

- other quality of life issues not listed above
- other people (for example family, friends, employers)

Many have had to rely on family and friends for help with basic hygiene needs, toileting, eating etc when their hand eczema has made it impossible to carry out these tasks because of a lack of mobility, pain and risk of infection.

- other issues not listed above.

The best example of successful treatment that highlights how alitretinoin can benefit someone with hand eczema is:

An elderly lady who for the first time in over 10 years was able to write her own Christmas cards and for the first time ever was able to cuddle her 3 year old grandchild

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).

Alitretinoin may not work for everybody with hand eczema but it will offer a new non-topical treatment that many have been hoping for for years.

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It is very unlikely that the side effects that are known would put anyone with hand eczema off trying alitretinoin.

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

Not that I know of

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?

All patients with hand eczema could benefit. It is hoped that the treatment may also be licensed for other skin conditions inc psoriasis, psoriatic arthritis

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.

Use of moisturisers and emollients that alleviate the hand eczema but do not clear it up all together and only marginally alleviate the symptoms

(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.)

Specifically for hand eczema alitretinoin will significantly improve the condition overall

(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.

1. Diepgen TL, Agner T, Aberer W et al. Management of chronic hand eczema. *Contact Dermatitis* 2007; 57(4):203-210.
2. Agner T, Andersen KE, Brandao FM et al. Hand eczema severity and quality of life: a cross-sectional, multicentre study of hand eczema patients. *Contact Dermatitis* 2008; 59(1):43-47.
3. Cvetkovski RS, Rothman KJ, Olsen J et al. Relation between diagnoses on severity, sick leave and loss of job among patients with occupational hand eczema. *Br J Dermatol* 2005; 152(1):93-98.
4. Ruzicka T, Lahfa M, Lynde C et al. Retreatment study of alitretinoin (9-cis retinoic acid) in severe chronic hand eczema refractory to topical treatment. Poster EADV-280 The 16th European Academy of Dermatology and Venereology Congress, April 2007.
5. Ruzicka T, Lynde CW, Jemec GB et al. Efficacy and safety of oral alitretinoin (9-cis retinoic acid) in patients with severe chronic hand eczema refractory to topical corticosteroids: results of a randomized, double-blind, placebo-controlled, multicentre trial. *Br J Dermatol* 2008;
6. Smit HA, Burdorf A, Coenraads PJ. Prevalence of hand dermatitis in different occupations. *Int J Epidemiol* 1993; 22(2):288-293.
7. Cvetkovski RS, Zachariae R, Jensen H, Olsen J, Johansen JD, Agner T. Quality of life and depression in a population of occupational hand eczema patients. *Contact Dermatitis* 2006; 54(2):106-111.
8. Fowler JF, Ghosh A, Sung J et al. Impact of chronic hand dermatitis on quality of life, work productivity, activity impairment, and medical costs. *J Am Acad Dermatol* 2006; 54(3):448-457.
9. Homey B, Bunemann E, Wiesner U, Schmitt-Hoffmann A, Maares J, Ruzicka T. Insights into understanding the mechanisms of action of alitretinoin in chronic hand eczema. Conference abstract. European Academy of Dermatology and Venereology . 2008.
10. Primary Care Dermatology Society & British Association of Dermatologists. Guidelines on the management of atopic eczema. Available at: <http://www.bad.org.uk/healthcare/guidelines/PCDSBAD-Eczema.pdf>. 2005.

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11. Niemeier V, Nippesen M, Kupfer J, Schill WB, Gieler U. Psychological factors associated with hand dermatoses: which subgroup needs additional psychological care? Br J Dermatol 2002; 146(6):1031-1037.
12. Warshaw E, Lee G, Storrs FJ. Hand dermatitis: a review of clinical features, therapeutic options, and long-term outcomes. Am J Contact Dermat 2003; 14(3):119-137.

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?

It would stop the disablement of many with hand eczema.

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

Many would remain disabled, in pain and depressed because of continued chronic hand eczema.

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.