

## Patient/carer group or patient expert statement

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:** Gladys Edwards

**Name of your organisation (if applicable):** 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)

**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.

(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.
- Infliximab is indicated for people with moderate to severe plaque psoriasis for whom other treatments have failed or are contra indicated. It offers relief from the itching, redness, soreness, pain and scaling of widespread psoriasis. Relief of these symptoms should lead to improved sleep patterns and an improvement in general health.
  - Psoriasis can have a profound social and psychological impact on people's lives – an Association survey in 2002 indicated that many people 59% of respondents felt their psoriasis affects their ability to go out and socialise; 49% that it prevented them forming relationships; 79% reported emotional distress and anxiety and 50% avoided physical activity because of discomfort or embarrassment.
  - Psoriasis impacts on the wider family – treatment regimes interfere with daily living and the constant need to clear the scales of psoriasis e.g. from furniture can be a source of frustration and embarrassment.
  - Improvement in the physical symptoms of the condition will lead to improvements in a patients mental health ,their ability to cope better on a day to day basis and help families cope.
  - Some patients with severe psoriasis are unable to work and an improvement in physical symptoms should 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 it 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 relative newness of Infliximab means that there are no long term data on efficacy or side effects.
  - Infliximab is administered in a hospital setting (as opposed to self administered) which may be inconvenient for some people.
  - People need to be fully aware of the potential side effects particularly the risk of infections. Individuals will make their own judgement about the risks and benefits of treatment as long as they are fully informed.

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?

Infliximab is clearly indicated for those people with more severe plaque psoriasis. It will not help those with mild to moderate disease or people with the less common forms of psoriasis such as pustular psoriasis on the feet although these can still have a profound impact in daily 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 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.)
  - Infliximab offers an overall improvement in psoriasis and is relatively fast acting. It should be possible by week 12 to determine if a person will benefit from the treatment.
- (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).
  - There may be a disadvantage in having to attend hospital for treatment – taking time out of work etc although the frequency of treatment is less than UV treatments.
  - 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?

- Infliximab represents another significant breakthrough in treatments for psoriasis and increases the range of treatments available for patients.

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

- There have been very few advances in treatments for psoriasis over the last 30 years. Infliximab is one of a range of new drugs that offer real 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.

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