NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal (STA)

Omalizumab for previously treated chronic spontaneous urticaria [ID707]

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: Allergy UK

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)

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iAppendix G – patient/carer organisation statement template

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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

1. Uncertainty about the different types and causes of urticaria
   - Define the clinical criteria for defining Chronic Spontaneous Urticaria (CSU)
2. Unrecognised pathway for treatment of CSU by most GPs
   - Clear treatment algorithm for primary care treatment and specialist referral
3. Omalizumab not used by many specialist dermatologists or clinical immunologists causing post-code lottery for patients and the need to travel very long distances for treatment
   - NICE Approval will create channel for specialist treatment in accessible hospitals

(b) Please list any short-term and/or long-term benefits that patients expect to gain from using the technology.

- the technology should define patient expectations for management of CSU and empower them to ask for better treatment from GP, thus optimising the prospect of quicker disease control and shorter duration
- treatment to reduce intense irritation and wheals in the short term and the recurrence of these wheals around the body long term
- relief of painful burning sensation
- treatment of angioedema (deep swelling)for many patient which is debilitating and affects normal function
- prevention of depression, which affects many CSU sufferers due to the physical affects
- restore normal sleep, improve emotions and social life
- ability to work normally again
- restore normal relationships with friends, family
- please employers

2. Disadvantages

Please list any problems with or concerns you have about the technology. Disadvantages might include:

- need for injection therapy may discourage a minority
- inconvenience of distance to travel for injections
- possible small risk of adverse reaction
- may need someone to accompany them to appointments
- cost of travel to access the technology, or the cost of occasional childcare

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

- I personally only know of one patient who had a reaction but was extremely ill beforehand with severe asthma and many side effects from long-term steroids.

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?

- Those with the most persistent and severe symptoms and those who react badly to other therapies would most benefit from omalizumab. Also those whose life is most severely affected, such as a mother who is trying to look after young children and work.

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.

High dose antihistamines – work for some
Monteleukast – from patient feedback, not very effective
Immunosuppressive drugs – help some but patients not happy to take for long
Steroids – usually work at high dose but effect wanes as dose reduced or stopped, also side effects not acceptable

(ii) If you think that the new technology has any **advantages** for patients over other current standard practice, please describe them. Advantages might include:
- best control than other treatments
- improvement in certain aspects of the condition
- monthly injection means no daily medication needed
-

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(iii) If you think that the new technology has any **disadvantages** for patients compared with current standard practice, please describe them. Disadvantages might include:

- attending hospital for injection

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.

None known

Are there any adverse effects that were not apparent in the clinical trials but have come to light since, during routine NHS care?

Not known

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.

Not research, only anecdotal from patients.

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 transform the lives of many previously well patients who currently cannot function normally but live in almost constant discomfort, often pain and misery.

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

A continuation of discomfort, misery and no hope for relief until the condition abates, for some, can be years.

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

Those who cannot travel to a specialist who offers the treatment.

Equality
NICE is committed to promoting equality of opportunity, eliminating unlawful discrimination and fostering good relations between people with particular protected characteristics and others. Please let us know if you think that this appraisal:

- could exclude from full consideration any people protected by the equality legislation who fall within the patient population for which [the treatment(s)] is/are/will be licensed;
- could lead to recommendations that have a different impact on people protected by the equality legislation than on the wider population, e.g. by making it more difficult in practice for a specific group to access the technology;
- could lead to recommendations that have any adverse impact on people with a particular disability or disabilities.

Please tell us what evidence should be obtained to enable the Committee to identify and consider such impacts.

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