

## Appendix D – Patient/carer expert statement template

## NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

## Single technology appraisal (STA)

**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.

The technology has made an enormous difference to my son's and the rest of the families lives.

(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.

Since using Tocilizumab all of the above have improved dramatically.

The difference it has made is quite unbelievable. I can not begin to imagine where our lives would be now if we hadn't been given the opportunity for this drug.

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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).

No disadvantages.

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

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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.

Unsure of any alternatives

(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.)

Condition improved very quickly. Found that it was a less stressful than previous drugs used. Even though regular hospital visits at first with the condition improving this trip was worth it.

(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).

No disadvantages

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**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?

Not aware of any.

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.

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**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 difference this technology has made to my son's and all the families lives has made an incredible difference.

I feel if other peoples lives could be turned around like ours it has got <sup>to</sup> be worth making this available on NHS.

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

This crippling disease would remain active causing <sup>severe</sup> pain, fever and distress, and prevent people from leading a normal life. I also feel if people were to continue leading such a life it could lead to mental illness in both patient and carer.

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

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**Other issues**

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

Please see personal statement.