Appendix D – Patient/carer expert statement template

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Single technology appraisal (STA)

Belimumab for the treatment of active autoantibody-positive systemic lupus erythematosus

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: Chris Maker

Name of your organisation: LUPUS UK

Are you (tick all that apply):

- a patient with the condition for which NICE is considering this technology? No
- a carer of a patient with the condition for which NICE is considering this technology? No
- 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) Yes, Director
- other? (please specify)
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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.

   A reduction in the use of other medications with their side effects i.e. steroids.

   Targeted suppression of the immune system to reduce the incidence and severity of lupus flares.

   A reduction in medical appointments with the GP, Hospital and possibly emergency admissions.

   (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.

   Improved quality of life due to the reduction in disease activity (incidence and severity of flares) coupled with a reduction in the use of other therapies that often have difficult and often long-term side effects, such as osteoporosis and weight gain, necessitating the use of other medications to counteract the side effects.

   A reduction in the physical symptoms such as pain and fatigue will assist mobility and the ability to work, as well as improve mental health, as depression is a common feature with lupus patients. Pain and fatigue are the

   Controlling this presently incurable disease is the key to overall well-being of the lupus patient. Lupus is largely invisible to family, friends and others as the symptoms and effects cannot be seen, other than when there is skin involvement, so the benefits of this technology can be seen to interlink improvements in the overall health of the lupus patient.

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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? (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).

All drugs have side effects and it is not known what these might be for this new technology.

Availability could be an issue if patients are required to travel long distances for treatment where there could be financial considerations regarding travel costs and also where a carer is involved. Some lupus patients have mobility problems and will always need assistance when travelling. Others may be unable to drive and will rely on family or friends for help as they may not be able to use public transport.

The potential of a ‘postcode lottery’ for this treatment.

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

Most of our members are pleased to hear about this new technology that is specifically for lupus. Optimism appears high, perhaps unduly so as the treatment is not applicable to everyone who has lupus.
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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?

This depends on how lupus affects the individual patient and certainly those with more severe symptoms are likely to benefit more, when the new technology is prescribed.

Overall all lupus patients will benefit as a new lupus specific treatment will be available that will have a high profile leading to greater awareness within the medical profession.

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.

NSAIDS
Anti-Malarials (hydroxychloroquine)
Steroids
Immunosuppressants
Biologics (Rituximab)

(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.)

If it reduces the incidence and severity of flares along with a reduction in the level of other medications, currently being taken, it will be of considerable benefit to some lupus patients.

By reducing the level of other medications being taken there should be a commensurate reduction in side effects.
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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:
- 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).

This depends upon how individual patients react to the new technology. It will also depend on how it is administered.

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 that I am aware of.

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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.
## NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

### Single technology appraisal (STA)

<table>
<thead>
<tr>
<th>Availability of this technology to patients in the NHS</th>
</tr>
</thead>
<tbody>
<tr>
<td>What key differences, if any, would it make to patients and/or carers if this technology was made available on the NHS?</td>
</tr>
<tr>
<td>The benefits to patients of this new technology being made available are outlined above in 1b.</td>
</tr>
</tbody>
</table>

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

Loss of quality of life that would be gained as otherwise they would continue to rely on current medications along with all the side effects that these entail.

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

Provided the administering of the technology is managed by health professionals as appropriate this should not prove to be a major issue.
Other Issues

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

Lupus is a multi symptom disease that is often difficult to diagnose and manage. The benefits of the new technology will greatly improve the outlook and quality of life for a significant number of lupus patients.