Appendix G – Patient/carer organisation statement template

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Single Technology Appraisal (STA)

Bevacizumab for the treatment of recurrent or advanced Ovarian cancer

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 nam [redacted]

Name of your organisation:
Target Ovarian Cancer

Are you (tick all that apply):

- an employee of a patient organisation that represents patients with the condition for which NICE is considering the technology?

Position: Public Affairs Manager

Appendix G – Patient/carer organisation statement template

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Single Technology Appraisal (STA)

Bevacizumab for the treatment of recurrent or advanced Ovarian cancer

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.

Three-quarters of women diagnosed with ovarian cancer have advanced disease (FIGO stage III/IV) at the point of diagnosis and the majority (70%) will develop recurrent disease at some point. Based on the clinical trial data available, the biggest impact that bevacizumab is likely to have on women with ovarian cancer is extending progression free survival (PFS) i.e. the time interval between recurrences and the requirement for treatment. Due to the high frequency of recurrence among women with ovarian cancer this technology has the potential to benefit the majority of the patient population.

(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:

Treatment for ovarian cancer can have a significant impact on a woman both physically and emotionally.

We have spoken to a number of women with recurrent ovarian cancer who have received Bevacizumab as part of their treatment. Benefits commonly identified by women include:

Best possible care – often women are aware of the poor outcomes associated with ovarian cancer. All of the women we have spoken to felt that by accepting bevacizumab as part of their treatment plan, they were giving themselves the best possible chance of prolonging the disease free interval.

Emotional/mental health – once a woman has been diagnosed with recurrent ovarian cancer, further recurrence will be expected as the cancer runs its course. The emotional impact of a woman's first recurrence following first-line treatment is particularly significant. For many, receiving the news that their cancer has returned can be more devastating than the initial ovarian cancer diagnosis. Improvement in PFS will allow give women valuable time to recover from the mental impact of recurrence and treatment, allowing them to resume normality, and live their lives as fully as possible.

In addition women have highlighted a number of emotional and psychological benefits of receiving bevacizumab in addition to their standard chemotherapy. All of the women we spoke to felt that they benefitted from regular appointments for their bevacizumab treatments after chemotherapy ended. These appointments brought them comfort and gave them a greater sense of confidence as and they felt that any medical problems would be picked up and acted upon quickly.

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Single Technology Appraisal (STA)

Bevacizumab for the treatment of recurrent or advanced Ovarian cancer

Some women commented that having bevacizumab gave them a psychological boost, they felt like they were getting a 'back up' treatment or 'added bonus' in addition to their chemotherapy.

Physical wellbeing - once a woman has recurrent ovarian cancer she will inevitably go through further treatment cycles for subsequent recurrences. A longer PFS is beneficial both in terms of supporting a better physical recovery, enabling the individual to successfully undergo subsequent treatment. It is thought that prolonging the interval between treatments is likely to make subsequent treatment more effective.

Choice – some women welcome the opportunity to be involved in making decisions about the care and treatments they receive, and feel they are able to take some control at what is typically a very uncertain time for many women.

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

Side effects – the Target Ovarian Cancer Pathfinder Study 2012 show that the side effects that women find the most difficult to cope with are: tiredness, feeling of being sick (nausea) and constipation (in relation to standard ovarian cancer treatments). Some of these side effects are also associated with bevacizumab, in addition to a broader range of potential side effects. There is the possibility that patients will be likely to experience side-effects over a longer time period due the likelihood that treatment with bevacizumab will include a maintenance phase once the chemotherapy phase is complete.

Potential side-effects are usually a consideration for women making decisions about treatment. However, feedback from women who have received bevacizumab is that the potential benefits of receiving bevacizumab are likely to outweigh the potential side effects associated with treatment.

Financial – bevacizumab is likely to be given in combination with chemotherapy over 6 cycles, and then ongoing as a maintenance therapy until the patients cancer progresses. This approach will require the patient to visit the hospital more regularly and the patient is therefore likely to incur greater travel costs. While for many women the perceived and actual benefits of the treatment will out weight the financial impact, for some this could be a significant problem.

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

Not that we are aware of

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Single Technology Appraisal (STA)

Bevacizumab for the treatment of recurrent or advanced Ovarian cancer

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?

Women with recurrent platinum resistant ovarian cancer will not benefit since they will not be eligible for platinum-based chemotherapy.

Women who are allergic to platinum chemotherapy will not benefit.

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.

(ii) If you think that the new technology has any **advantages** for patients over other current standard practice, please describe them. Advantages might include:

Including bevacizumab as part of standard treatment for recurrent ovarian cancer will for some women prolong progression free survival and possibly overall survival.

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

Perceived disadvantages of including bevacizumab as part of standard treatment for recurrent ovarian cancer are the potential for extending a) length of time women have to tolerate side effects and b) the potential range of side-effects profile. Bevacizumab has a unique side-effects profile compared to platinum drugs and paclitaxel. This treatment is also likely to require more frequent visits to the hospital. However, feedback from women living with ovarian cancer suggests that in most cases the advantages will outweigh the disadvantages.

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.

Patients receiving the drugs as part of their standard NHS care are likely to have a similar experience to those who received it in the context of the clinical trial, particularly in the way the drug is administered and the side effects they are likely to experience. Patients who participate in clinical trials often report feeling very well

cared for due to the additional tests and check-ups that are necessary as part of participating in a clinical trial. This greater sense of being cared for and feeling of security it gives the patient is likely to be unique to the clinical trial setting and won't translate to the standard care received on the NHS. Also, there is the possibility that side effects will be identified and treated more quickly in the clinical trial setting as patients are under closer observation.

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 we are aware of

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?

Clinical trial data shows a significant improvement in progression free survival when bevacizumab is given to patients in addition to standard chemotherapy for recurrent ovarian cancer. This improvement in PFS is particularly significant from the patient perspective as women with ovarian cancer live with the constant threat of further recurrence. Improving progression free survival gives women and their families much valued time, freeing them from the side effects of treatment, and helping them regain aspects of their 'normal' life outside of the hospital setting.

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

Bevacizumab is the first new treatment to significantly improve outcomes for women since the introduction of paclitaxel to standard treatment in the early 1990's. It is imperative that effective new treatments are made available.

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

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:

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Single Technology Appraisal (STA)

Bevacizumab for the treatment of recurrent or advanced Ovarian cancer

- 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.

Other Issues

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