

**NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE**

**Single technology appraisal (STA)**

**Bevacizumab for the treatment of recurrent 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 name:**

Annabel Chillingworth

**Name of your organisation:**

Nominated by Ovarian Cancer Action (Charity)

**Are you (tick all that apply):**

- a patient with the condition for which NICE is considering this technology?  
**Yes**
- 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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**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 reasonable extended time in remission with a reasonable quality of life. A quality of life where if pain/discomfort are suffered they can be mitigated with pain control and the ability to take part in 'normal' life activities.*

*I speak as someone with Ovarian Cancer, I am at present taking Cediranib ( V.D.A, I believe this drug works in a similar manner as the discussed technology) as part of a trial after a recurrence of Ovarian Cancer.*

*It is very likely that this has extended my expected maximum period of remission from 8 months to 18 months (and hopefully more). I cannot begin to express how much this 'extra time' has meant to myself and my family. It has been made clear that there is no cure and that I have a limited life expectancy. However this 'extra time' has allowed for my children to become teenagers, to us as a family to come to terms with our situation. To acknowledge and accept that I will not be there in the future but that I am here today.*

*It has given us time to leave behind the drama of the diagnosis, the chemo, and to live together mindfully but without the fear of cancer just knowing that it is a part of our life and we have been lucky to have this time*

(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.

*As I have mentioned above, a prolonged period of remission allows you and your family to move beyond the initial diagnosis. To return to work or take the opportunity to re write the script of your life. In terms of mental health it creates thinking and*

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*healing time. The exploration of more options, for example supporting your body by eating well and exercising.*

*For your family they have a chance to be with you in a more ordinary way as opposed to one defined by the panic of the clock ticking.*

*Holding the cancer at back obviously may provide relief from physical symptoms. It certainly has for me.*

**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).

*It is possible that the discussed technology may have side effects that mean that outweigh the advantages. With the drug I take this has certainly been the case with some people. Some women stopped taking the drug as the side effects of diarrhoea and bowel problems/pain were too impacting on their life. Possibly making it unsafe. Particularly from those weakened by age and or disease.*

*In my case I have suffered the above side effects. These have impacted on my life in that it would have been extremely hard to return to work. There have been periods where I have suffered extreme abdominal pain and almost uncontrollable diarrhoea. However I am fit, in that I run each day. I eat with extreme care.*

*Through diet I have managed to mitigate/control the side effects. I have taken pain-killers and I also have a very patient husband! Willing to find a loo at a moments notice. Because of the family I have been determined to continue with all our normal activities. Some activities have been challenging For example going camping and eating out with friends have often been hard. I have made every effort never to mention the pain or the problems, to try hard not to let it change my outlook, to get in the way. To define who I am. To moan.*

*For the privilege of being with my children and my husband for this time I would have borne more pain!*

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*I would stop treatment only when the level discomfort changed my personality from someone who, I judge to be, a positive force in the life of our family/community, to someone who is a burden and a drain.*

*I think that the patient should be given the option.*

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

NA

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?

NA

**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.

(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.)

*I do not know enough about the technology to answer this question.*

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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).

I do not know enough about the technology to answer this question.

**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.

I do not know enough about the technology to answer this question.

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

I do not know enough about the technology to answer this question.

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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.

No

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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?

*Increased choice of treatment options. Increased survival rates. Improved optimism about the condition for sufferers.*

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

*There is very few options for patients with Ovarian Cancer. The treatment for this cancer has not moved forward significantly in comparison with Breast Cancer. In funding this treatment option patients and medical teams would feel that there was more to offer and a commitment to improve the situation of sufferers. Also an acknowledgement that 'more time' is of great value.*

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.