

**NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE**

**Single Technology Appraisal (STA)**

**Bevacizumab in combination with paclitaxel and carboplatin for the first-line treatment of 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:**

[REDACTED]

**Name of your organisation: Ovacome**

**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?

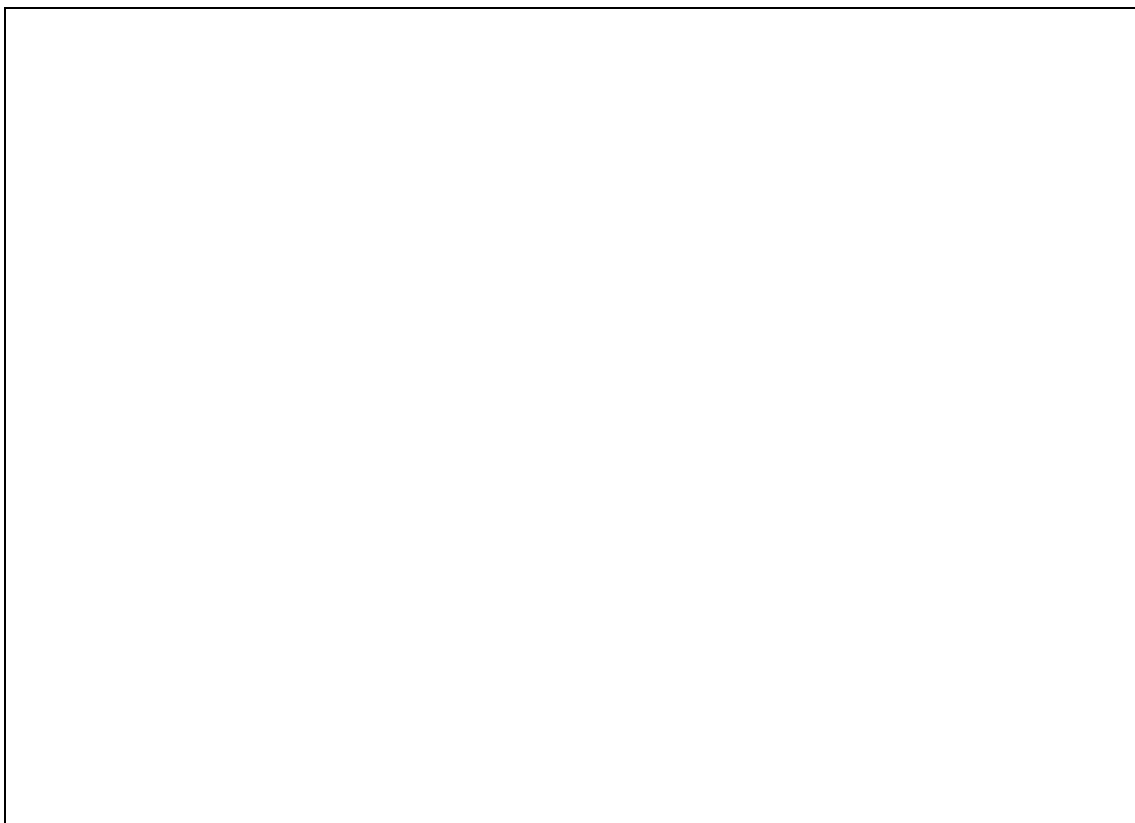
an employee of a patient organisation that represents patients with the condition for which NICE is considering the technology? If so, give your position in the organisation where appropriate (e.g. policy officer, trustee, member, etc)

other? (please specify)

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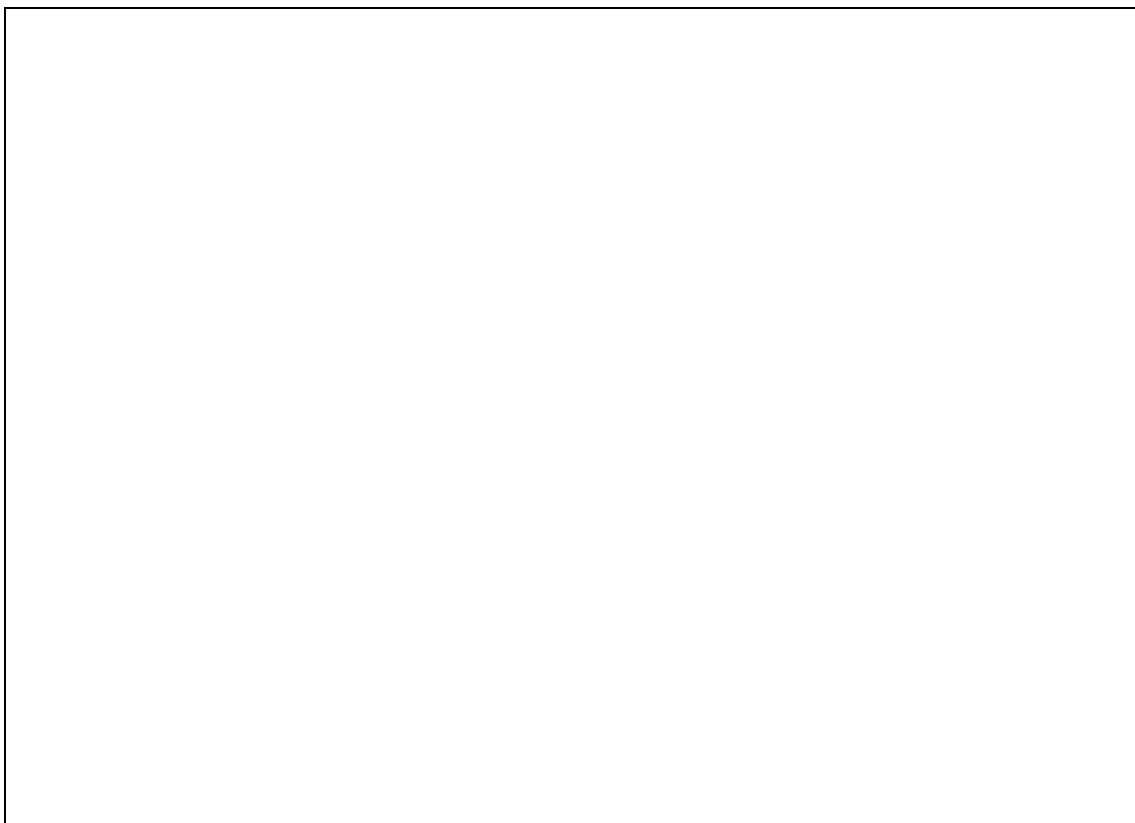
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**What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition ?**

**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.

*Survival – Phase three studies demonstrate significant progression free survival; something sadly lacking in this difficult to treat disease*

*Disease progression monitoring. Maintenance therapy is new to ovarian cancer. Women having greater contact with the health care team will provider greater scope for disease progression monitoring and intervention in other survivorship issues such as side effect monitoring/intervention*

(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 above – Progression free survival has been clearly demonstrated. Associated with this is the critical psychological importance given by all those touched by the diagnosis that the NHS is providing the best chance of survival and access to novel treatment modalities.*

*This technology has demonstrated that it prevents/delays disease recurrence for some women. Once ovarian cancer recurs further treatment is palliative.*

**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.

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- 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).

*Maintenance therapy places certain burdens on the woman with ovarian cancer and their families. The prolongation of hospital intervention is associated with increased financial burden and for some women this was a reason for not participating in the ICON 7 studies. They expressed a wish to get their treatment completed as soon as possible; however since the results of the Avastin trials Ovacome has not received any feedback of this nature.*

*Women with ovarian cancer are individual who will choose on an individual basis about the level of side effects they are willing to tolerate. This is for the woman and her medical team to decide on a case by case basis, however research by M Slevin clearly demonstrates that people with cancer are far more willing to tolerate side effects than their clinicians thought. ([BMJ](#). 1990 Jun 2;300(6737):1458-60.)*

*The most significant impact in terms of 'side effects' is the impact of not being able to have surgery during treatment. This will naturally lead to challenges for clinicians and patients who require unplanned surgical intervention. We have no experience of this to bring to bear on your considerations.*

*To quote one member – “The side effects of Avastin are nothing compared to being told you have cancer”*

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

*Not really. The only clamour on the helpline and on our web platforms (Over 1000 members) has been questions of access.*

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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?

*I understand that women with more bulky/post operative residual disease gain the greatest advantage in administration of Avastin*

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**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.

*There are no licensed comparable treatments*

(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.)

*As previously stated. , this treatment is an addition to existing treatment, as such it does not negate any of the undesirable elements of the previous treatment.*

(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).

*Previously described*

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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.

*As the treatment does not yet have NICE approval its main impact on patients is the need to go through the additional stresses of the Cancer Drugs Fund. Otherwise the patient experience seem to have been the same as during he clinical trials*

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

*None that I am 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.

*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?

*A positive NICE determination would allow a normalisation of the oncology consultation; with no need to trouble people with conversations about NHS funding structures and limitation*

*Women would be able to determine for themselves whether they wish to receive the product, and a consequential improvement in progression free survival would be experienced*

*The current situation is not ideal – Women who have had their individual funding requests submitted have expressed significant anxiety about the process.*

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

*If NICE does not approve Avastin the Cancer Drugs Fund are highly unlikely to fund the prescription of Avastin. This will have a significantly negative impact for the hundreds of women who might otherwise have had access to choose to receive this treatment. This will be associated with significant psychological distress*

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

Apart from the known contra-indications I am not aware of any

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**Equality**

Are there any issues that require special attention in light of the NICE's duties to have due regard to the need to eliminate unlawful discrimination and promote equality and foster good relations between people with a characteristic protected by the equalities legislation and others?

No

**Other Issues**

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