NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal (STA)

Aflibercept for the treatment of metastatic colorectal cancer which has progressed following prior oxaliplatin-based chemotherapy

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:

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.

I would definitely expect the technology to improve the patient's quality of life in the short term by reducing the physical symptoms of the disease. I was diagnosed with stage 4 bowel cancer, which had spread throughout my liver and into my lungs. Prior to starting treatment, I was experiencing a number of symptoms caused by my liver tumours. These included fevers caused by intermittent 'spikes' in body temperature, night sweats, nausea, loss of appetite and a loss of interest in doing things that I used to enjoy. I felt generally unwell most of the time and it became increasingly difficult

After the second round of chemotherapy, there was a noticeable reduction in symptoms. As my treatment progressed, I gradually regained my appetite and the incidences of fever and night sweats became much less frequent.

The technology could cause a significant improvement in some cases and may change the prognosis for some people by enabling surgery to take place on previously inoperable tumours. I was able to have a liver resection following chemotherapy.

(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.

I would expect the majority of patients to benefit from this technology to some extent, primarily by reducing the physical effects of the condition, as discussed above. This in turn could lead to the following benefits:

Short-term

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- Physical symptoms should be reduced (as discussed in part a) which will reduce pain and discomfort.
- This could in turn lead to the patient feeling generally better, which could improve their mental health and their capacity to continue to work/socialise etc.
- I found that this increased sense of wellbeing made me feel more positive about my situation, despite having been diagnosed with an incurable condition.
- There were positive short term benefits for my family and friends too, as they saw that I was starting to improve.

Long term
In my case, significant long-term benefits were achieved as I continued to improve throughout the course of chemotherapy. By the end of it, the tumours had responded sufficiently well for me to be eligible for a liver resection and I had regained some strength, which increased my chances of coping with major surgery.

I would not expect all patients to achieve the same level of benefit from this technology, but I think that everyone should be given access to it in the first instance as it is possible that their prognosis could improve significantly.

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).

The technology may cause some physical side effects such as tiredness, nausea etc. Only the individual patient using the technology would be able to decide whether or not the side effects outweighed the benefits, so it would not be appropriate for me to comment further.

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3. Are there differences in opinion between patients about the usefulness or otherwise of this technology? If so, please describe them.
Not known.

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?
It is probable that patients will benefit to a varying degree, as is the case with existing technologies. I do not know whether this would apply in terms of groups of patients.

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.
Current standard practice would be to treat the condition with combination chemotherapy.

(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.)

This technology works in a different way to existing technologies, so it may be that for some patients it is more effective than existing alternatives. This could lead to a greater improvement in their condition.

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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 am not aware of any specific disadvantages compared to standard practice as there are some disadvantages, eg side-effects of treatments, which will occur with all technologies used to treat the condition.

Equality and Diversity

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:

- 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

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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?

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?

If this technology is made available on the NHS, then it could make a significant difference to some patients. If it proves to be more effective than existing treatments, either in terms of halting the progress of the disease or potentially reversing it, then there will be a significant benefit to the patient. New technologies should be available to everyone whose condition they may help, at least in the first instance, to give the patient the best chance of having better quality of life and potentially a longer life than they otherwise would.

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

If this technology is not made available, some patients may be deprived of the potential to enjoy better quality of life for longer.

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.