NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal (STA)

Abiraterone acetate for the treatment of metastatic hormone relapsed prostate cancer not previously treated with chemotherapy [ID503]

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:
Prostate Cancer Support Federation

Are you (tick all that apply):

- a patient with the condition for which NICE is considering this technology? X
- 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) X
- 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.

Many advanced prostate cancer patients with a metastatic condition cannot tolerate chemotherapy either because of their ECOG and or another chronic condition. At the current time making them start a chemotherapy cycle and then become ill is both unnecessary and inhumane. For them having the availability of Abiraterone without the need for chemotherapy is a major step forward in prolonging their life.

The above is the major advantage.

The disadvantage is that some patients for whom chemotherapy is the right treatment pathway may try and miss this step because the of the concern over the toxicity of Docetaxel. This would be a shame because it adds a step to their life extension.

Of course not all patients can tolerate Abiraterone and its hepatic side effects.

In short the major advantage can be gained by the patient's oncologist giving the right guidance.

(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.

For those patients that can tolerate Abiraterone it has significant quality of life enhancing factors. Reduction of pain, extension of life, permitting men to enjoy activities that they had been excluded from before this treatment. The family/ carer will benefit from the quality of life improvement.

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The technology is pill based so that travel does not have to a consideration.

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).

As mentioned before the drug can interact with the liver and therefore is not a treatment for all men with metastatic cancer. Regular blood tests will show the clinician if this is the case.

The common side effects are those tolerated by men who will have been taking a LHRH analogue and so the side effects of tiredness etc. will not be a problem and many are overcome with a good diet and plenty of non alcoholic fluid.

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

No. Patients who cannot tolerate Chemotherapy are not divided on the treatment and the good that can come form it.

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?

As mentioned previously mentioned those that have a problem tolerating chemotherapy will benefit enormously from this pathway.

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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.
The obvious alternative to chemo naïve treatment in this area is Enzalutamide which has no effect on the liver but offers in a different way the same advantages.

(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.)

Our experience through our members of this treatment is good. It does what is says on the tin; extends life, is easy to administer in its pill form thus no travel. As mentioned earlier most side effects are tolerated well.

(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).

There are no major disadvantages to that can tolerate this treatment

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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.

The average opinion seems to be among the membership of the PCSF that Abiraterone extends life greater than that portrayed in the phase 3 trial.

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

Perhaps the liver effect is more pronounced

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?

This has already been articulated at least twice in earlier questions

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

Men would be left with Doxetaxel as their only treatment.

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

Already spelt out – those with liver issues

Other Issues

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