NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal (STA)

Enzalutamide for the treatment of metastatic hormone relapsed prostate cancer previously treated with a docetaxel-containing regimen

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: Hugh Gunn

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?

- a carer of a patient with the condition for which NICE is considering this technology?
- ✓ Hon. Treasurer. 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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Single Technology Appraisal (STA)

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.
Increase in life expectancy
Less bone pain
Less side affects (liver problems) than the comparable drug (Abiraterone)
Easily administered, four capsuals daily taken at home
To feel well enough to take an active and productive role in society
To have the delight of seeing your grandchildren grow and have an active part in their upbringing and development
A huge increase in the quality of life

(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 **Increased life expectancy**
- physical symptoms a **lessening of physical symptoms**
- pain **decease in cancer related pain**
- level of disability - **decrease or zero level of disability**
- mental health **No problems with mental health, but to have the joy of being alive**
- quality of life (lifestyle, work, social functioning etc.) **Good quality of life style in every way, including the ability to continue working if desired.**
- other quality of life issues not listed above **The opportunity to see children get married and to see grandchildren be born and grow.**

- other people (for example family, friends, employers) **Feeling well enough to enjoy activities and socialise with family and friends. To have enough energy to work whether on a paid basis or in a voluntary capacity.**

- other issues not listed above. **The ability to go on holiday and not to have to worry about having to cut short by the dreaded prostate cancer**

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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. **None that PCa patients have experienced for many years and become used to**
- difficulties in taking or using the technology **None, 4 easily swallowed capsules daily taken at home**
- side effects (please describe which side effects patients might be willing to accept or tolerate and which would be difficult to accept or tolerate) **None**
- impact on others (for example family, friends, employers) **My family and friends will have to put up with my company for a considerable time longer**
- 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). **None**

3. Are there differences in opinion between patients about the usefulness or otherwise of this technology? If so, please describe them.
None that I am aware of

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 very important that Patients who have been on Abiraterone are given Enzalutamide after Abiraterone has failed. In my case, Abiraterone worked well for 8 months and then it started to affect my liver. I have been on Enzalutamide for 10 months now and because it is nonsteroidal in it's nature, my PSA is steady at 0.5 and my AST liver level is down from 580 to 21. If the current CDF indefensible rules had been applied, by now, I would have been in a very bad place indeed

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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 with existing treatments for this condition in the UK.

(i) Please list any current standard practice (alternatives if any) used in the UK.

Abiraterone

(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.)

Abiraterone is steroidal in it's nature and so in some patients it can affect the liver. From personal experience, this doesn't happen with Enzalutamede.

(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).

None that I can Think of

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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

None

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.

From personal experience, yes.

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Single Technology Appraisal (STA)

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. **Not known**

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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?

Patients would not only live longer, but have good quality of life. They would be able to fulfil their role in society and the carers role would be diminished. If the carer is the patients wife/partner, the relationship would revert back to one of normality

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

Patients would die

Are there groups of patients that have difficulties using the technology?
None

Other Issues

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

Yes. All of these advanced prostate cancer treatments cause osteoporosis. NICE should urgently reconsider the treatment pathway for advanced prostate cancer to include bone health. As it stands, this is not only morally wrong, but fails to comply with the government's own equality legislation. There could also be a Human Rights issue here.

The overall cost of allowing this drug should not impact greatly on the NHS, because patients would not be on both.

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