Appendix G – patient/carer organisation statement template

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: [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?

- a carer of a patient with the condition for which NICE is considering this technology?

✓, **Trustee, Hon. Treasurer unpaid**. 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.

Increase in life expectancy
Less bone pain
Less side affects (liver problems) than the comparable drug (Abiraterone)
Easily administered, four tablets daily taken at home

(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 pain**
- level of disability - **decrease or zero level of disability**
- mental health - **No problems with mental health**
- quality of life (lifestyle, work, social functioning etc.) – **Good quality of life style in every way, including the ability to continue working**
- other quality of life issues not listed above – **The opportunity 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

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**
- difficulties in taking or using the technology - **None**

- side effects (please describe which side effects patients might be willing to accept or tolerate and which would be difficult to accept or tolerate) – **There are no significant side affects.**
- impact on others (for example family, friends, employers) **- None**
- financial impact on the patient and/or thier family (for example cost of travel needed to access the technology, or the cost of paying a carer) – **None. There are four easily swallowed tablets every day, taken at home.**

3. Are there differences in opinion between patients about the usefulness or otherwise of this technology? If so, please describe them. **None that I know 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? **Life saving benefits for patients who for some reason cannot tolerate Abiraterone. Abiraterone can cause liver damage, with Enzalutamide this doesn't seem to be a problem.**

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.

Abiraterone

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(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 of 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 works very well for many patients. However, there is a significant number who cannot be treated with it because of the side affects it produces, Liver damage being one of them. Because Enzalutamide is none steroidal in it's nature, it is tolerated by the liver and patients can live a normal life.

(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).

From personal experience, none of the above

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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.

From personal experience, yes

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 know 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

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?

There is only one comparable drug which is Abiraterone. Enzlutamide clearly works for many patients where Aberaterone has failed. Therefore, it can be truly said that this drug is a real life saver. Not only that, there is a real quality of life enjoyed by patients taking Enzalutamide.

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

Patients who need Enzlutamide would die. Patients would not take both Abiraterone and Enzalutamide, it would be one or the other. Therefore, the difference in overall cost to the NHS should not be significant.

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

No

Equality
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.

There are no equality issues

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

As all of these new drugs extend life, as a matter of urgency , NICE should reappraise the treatment pathway for advanced prostate cancer to include treatment for bone health. The importance of this cannot be understated!

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