Appendix G – patient/carer organisation statement template

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?
- 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)
- Hon. Treasurer, Trustee. **Unpaid**
-
- 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.

Abiraterone is proven to be a very successful treatment. but at the moment it can only be given after putting the patient through the debilitating affects of chemotherapy. It not only extends life but gives a good quality of life, reversing some of the pain associated with advanced prostate cancer

(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

It gives the patient the ability to live a normal life. This includes working if desired, seeing children get married, seeing grandchildren born and develop

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 thier family (for example cost of travel needed to access the technology, or the cost of paying a carer)

In a few patients, abiraterone can cause liver problems.

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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.

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?

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.

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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)

Current standard treatment is to give docitaxel based chemotherapy first. This can be a 6 month course with quite debilitating side affects. Extreme fatigue, risk of infection, loss of memory and confusion numbness in toes, broken finger and toe nails, hair loss and loss of appetite to name but a few.

Some of these are permanent. Numbness in the toes usually stays and makes walking clumsy. Finger nails stay weak and brittle, meaning that they are constantly breaking and uncomfortable. I also wonder is the more serious side affect of liver damage would be lessened if chemotherapy was not given.

It would be hugely beneficial to the patient if chemotherapy was not given first and all of the above could be avoided. It would also be cost affective, because the cost of chemotherapy would be offset against the cost of giving abiraterone.

In my own case, the benefits of chemotherapy only lasted for 2 months, so I went through all of the nightmare of treatment to no avail.

(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).

Possible liver problems in very few patients, but would this improve if the liver hadn't been put under such stress by chemotherapy?

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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.

NA

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

Not known

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

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?

As already stated, chemotherapy would still be given, the NHS might save a little money but not much and patients would suffer greatly

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

Chemotherapy would still be given, the NHS might save a little money but not much and patients would suffer greatly

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.

None

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

Bone health. Because there is no NICE pathway which includes bone health for prostate cancer, this is a huge issue and likely to get much worse.
As was stated in the enzaulamide appraisal, catastrophic spinal compression is quite rare in advanced prostate cancer, but both abiraterone and enzalutamide carry an 8% risk. This is because, in the past, advanced prostate cancer patient usually died before this became a problem. Now, with very successful life extending drugs it is going to become serious one. This could be so easily avoided if bisphosphonates or denosumab could be given to prevent the osteoporosis caused by hormone treatment . In other cancers, this is standard practice and there is no clinical reason to refuse it.