NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Patient/carer expert statement (STA)

Enzalutamide for treating metastatic hormone-relapsed prostate cancer not previously treated with chemotherapy

Personal information

Name: [redacted]

- Nominated by Prostate Cancer UK
- Prostate Cancer UK has submitted a statement.
- I agree fully with my sponsoring body's statement, but will also submit a brief personal view, following the line of questions and prompts in the Patient/Carer expert statement template.
- I was diagnosed with prostate cancer in 2004 and successfully treated in 2005. As far as I am aware, my cancer is in full remission.
- Since 2007, I have been an active awareness, support and campaigns volunteer for Prostate Cancer UK (formerly The Prostate Cancer Charity).
- While I have no personal experience of the condition described above, my work for PCUK brings me into contact with men and their families in this later and critical stage of the disease.
- While I am familiar with my nominating body's submission and contributed to the survey which informs it, I had no part in its writing.

Living with the condition

Men with advanced stage prostate cancer experience a range of debilitating side effects following hormone treatment, in addition to the recurring progression of the disease. These side effects can include physiological problems associated with osteoporosis, breast swelling and tenderness, nausea, hot flushes, erectile dysfunction, urinary incontinence, fatigue, weight gain and so on. These physiological problems are often also accompanied by psychological issues including depression and lowering of self esteem arising from perceived 'loss of masculinity', and loss of feelings of self worth and dignity. Confronted again with an uncertain future, their quality of life is further considerably reduced by the side effects of the failed treatment.

Current practice for treating the condition

For many men whose cancer no longer responds to hormone therapy the standard treatment is likely be chemotherapy, a prospect which is dreaded by many, given the wide-spread reports they receive of its appalling side-effects, the inconvenience of the treatment regime and the uncertainty of its long-term benefits. Some describe chemotherapy as 'worse than the disease itself' and too high a price to pay for the loss of quality of life. These men are realistic about their mortality and rate quality of life as more significant than mere continuation of life at any cost. By 'quality of life' they refer to being able to enjoy to the full their remaining time with family and loved ones; of being well enough to get their affairs in order and to achieve some personal goals while they are still able. For these men, delaying the entry to the chemotherapy pathway is of high priority. On the other hand, for some men chemotherapy is not an option due to other health conditions inimical to the treatment. Further, some men may simply choose not to undergo this treatment.

Abiraterone appears to be a suitable treatment for some men in the foregoing categories, and for those for whom it is not appropriate, enzalutamide appears to be an important alternative.

The advantages of the treatment being appraised

The principal advantage of the treatment would appear to be delaying, or avoiding, chemotherapy for metastatic hormone relapsed prostate cancer, or providing an option for men with this condition for whom chemotherapy is unsuitable or unavailable, or for whom Abiraterone is unavailable.

The benefits from the treatment being appraised might include:

- Providing clinicians with an alternative treatment where options are already limited.
- Prolonging the life of men with this condition.
- At best enhancing, or at worst not diminishing, patients' quality of life at a time when preceding treatments seem to have failed, or ceased to be effective.
- Having access to treatment that is self-administered in the home in an easy, straight-forward manner in pill form.
- Having access to treatment that has minimal deleterious effects upon the patient's family or carer.

These benefits represent some advantages over other NHS treatments in England.

These views are derived from my encounters and discussions with men with this condition, represented here as fairly and as objectively as I am able. I have encountered no dissenting views.

The disadvantages of the treatment being appraised

I am not aware of any disadvantages, nor have any been brought to my attention by my informants.

Concerns about current NHS treatments

Most concerns seem to be generic, rather than specific to this treatment. 'Luck' is often perceived to be at the heart of the availability of treatments in late-stage prostate cancer, along with the uncertainty of availability of funding for new treatments: apparent inconsistencies in practice from one area to another: the view that 'the authorities' do not pay sufficient attention to what those who are actually experiencing the disease are saying about - for example - the quality of life, and what is really important when someone is facing the end of his life.

The main concern about this treatment is that it won't be available as an option, or that a decision to adopt it will have restrictions imposed upon its prescription relating to previous treatments.

The patient population

The main beneficiaries will be men with metastatic hormone relapsed prostate cancer who cannot, or who do not wish to receive, chemotherapy. A further group of beneficiaries would be those men who have important reasons of their own for wishing to delay chemotherapy by a reasonable amount of time, in the order of a year or more.

I am not aware of any group that might benefit less from the treatment, save those for whom the drug may be unsuitable on medical grounds.

Research evidence on patient or carer views of the treatment

I refer to the data provided by my nominating body, Prostate Cancer UK *(q.v.)*

Equality

I am not aware of any issues relating to the treatment being appraised.