NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Patient/carer organisation submission (STA)

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

Thank you for agreeing to give us your views on this treatment that is being appraised by NICE and how it could be used in the NHS. Patients, carers and patient organisations can provide a unique perspective on conditions and their treatment that is not typically available from other sources. We are interested in hearing about:

- the experience of having the condition or caring for someone with the condition
- the experience of receiving NHS care for the condition
- the experience of having specific treatments for the condition
- the outcomes of treatment that are important to patients or carers (which might differ from those measured in clinical studies, and including health-related quality of life)
- the acceptability of different treatments and how they are given
- expectations about the risks and benefits of the treatment.

To help you give your views, we have provided a questionnaire. You do not have to answer every question — the questions are there as prompts to guide you. The length of your response should not normally exceed 10 pages.

1. About you and your organisation

Your name: [redacted]

Name of your organisation: Prostate Cancer UK

Your position in the organisation: Senior Policy Officer

Brief description of the organisation: Prostate Cancer UK is the UK's leading charity for men with prostate cancer and prostate problems. We support men and provide information, find answers through funding research and lead change to raise awareness and improve care. The charity is committed to ensuring the voice of people affected by prostate disease is at the heart of all we do.

The following pharmaceutical companies sponsored and/or supported activities carried out by Prostate Cancer UK from April 2013 – March 2014:

- Janssen UK
- Astellas Pharma UK
- Lilly UK

Prostate Cancer UK has a policy that funding from pharmaceutical and medical device companies will not exceed 5% of its total annual income. During the financial year 2013/2014 donations from such organisations, expressed as a percentage of our total annual income, were less than 0.02%.

2. Living with the condition

What is it like to live with the condition or what do carers experience when caring for someone with the condition?

Men with prostate cancer can experience significant levels of side effects following treatment. Physiological side effects can include: osteoporosis, breast swelling and tenderness, chills/fever, nausea, headaches, hot flushes, difficulty having or maintaining an erection, infertility, loss of libido, muscle aches, pain, bowel and urinary incontinence, problems passing urine, fatigue, weight gain, and weight and muscle loss. Psychological side effects, such as anxiety and depression, have also been observed (1–4).

3. *Current practice in treating the condition*

Which treatment outcomes are important to patients or carers? (That is, what would patients or carers like treatment to achieve?) Which of these are most important? If possible, please explain why.

In an opinion survey we commissioned of 412 people affected by cancer, respondents placed a high value on treatment that can give people approaching the end of their lives precious extra time with friends and family: 98% of respondents indicated that priority should be given to the ability of a drug to extend life (5).

Our survey carried out in support of this submission asked men and their friends and family members for their views on what extra time towards the end of life meant to them. Numerous respondents stated *"everything"*. A large number of respondents placed value on extending life as a means to spend extra time with loved ones, while prolonging life was valued by some men as a means to achieve closure and to prepare for the end of life. Other men placed value on treatments that would enable them to continue to participate as a full member of society, while others highlighted personal fulfilment benefits to be gained from life extending treatment (6).

99% of respondents to our opinion survey indicated that priority should also be given to the ability of a drug to improve QoL, with the highest priority given to pain relief (5). Our survey in support of this submission revealed the same theme, when respondents were asked for their views on what extra time towards the end of life meant to them (6).

For patient quotes, please refer to appendix 1.

What is your organisation's experience of currently available NHS care and of specific treatments for the condition? How acceptable are these treatments and which are preferred and why?

Whilst abiraterone is an acceptable treatment for this population, some men are unable to complete treatment with it, as a consequence of dose-limiting toxicity. For these men, enzalutamide is an important alternative option.

Enzalutamide has been shown to provide a significantly longer time to initiation of cytotoxic chemotherapy than abiraterone (17.2 months (7) vs 9.7

months (8), respectively). Respondents to our survey in support of this submission expressed a strong preference for avoiding or delaying cytotoxic chemotherapy (6).

For patient quotes, please refer to appendix 2.

In addition, for some men, chemotherapy is not an option. Some men may not be fit enough to tolerate chemotherapy, some men may wish to delay chemotherapy, with its devastating side effects, and some men may simply choose not to be treated with chemotherapy.

"My husband does not want chemo so enzalutamide would be a wonderful choice" – partner of a man diagnosed with prostate cancer.

"I had abiraterone (Zytiga) for 15 months through the Cancer Drugs Fund until it stopped working recently – as I am asymptomatic and look and feel well, I do not wish to have heavy duty chemo i.e. Docetaxel at this stage – I am lucky to be a member of BUPA who are now funding me to be on enzalutamide (Xtandi)" – man diagnosed with prostate cancer.

At least 20 to 40% of patients with metastatic prostate cancer never receive chemotherapy (9–11). Enzalutamide, therefore, addresses an important unmet need in a population that is not served by current therapies through baseline commissioning.

Abiraterone is not available to chemotherapy naïve prostate cancer patients with visceral disease (12). This is because the COU-AA-302 study of abiraterone excluded patients with visceral disease (8). As the PREVAIL study of enzalutamide included patients with visceral disease and demonstrated clinical benefits in this group (7), enzalutamide is available for these patients via the Cancer Drugs Fund (12). Enzalutamide is, therefore, an important treatment option for these patients who are not served by current therapies.

4. What do patients or carers consider to be the advantages of the treatment being appraised?

Benefits of a treatment might include its effect on:

- the course and/or outcome of the condition
- physical symptoms
- pain
- level of disability
- mental health
- quality of life (such as lifestyle and work)
- other people (for example, family, friends and employers)
- ease of use (for example, tablets rather than injection)
- where the treatment has to be used (for example, at home rather than in hospital)
- any other issues not listed above

Please list the benefits that patients or carers expect to gain from using the treatment being appraised.

Respondents to our survey in support of this submission highlighted the benefits of delaying chemotherapy and the importance of having a treatment option where chemotherapy is unsuitable (6).

For patient quotes, please refer to appendix 3.

Please explain any advantages that patients or carers think this treatment has over other NHS treatments in England.

Respondents to our survey in support of this submission described feelings of hope where treatments prolong life, and highlighted the importance of treatment choice (6).

For patient quotes, please refer to appendix 4.

If you know of any differences in opinion between patients or carers about the benefits of the treatment being appraised, please tell us about them.

One respondent to our survey in support of this submission (a man diagnosed with prostate cancer) stated that a treatment should not be taken unless it is a cure.

One survey respondent (a man diagnosed with prostate cancer) stated that it was ‘not important at all’ for enzalutamide to become a treatment option for men with advanced prostate cancer who have not previously received

chemotherapy, and that the treatment would not have any benefits. No reasons were given against these responses (6).

5. What do patients and/or carers consider to be the disadvantages of the treatment being appraised?

Disadvantages of a treatment might include:

- aspects of the condition that the treatment cannot help with or might make worse
- difficulties in taking or using the treatment (for example, injection rather than tablets)
- side effects (for example, type or number of problems, how often, for how long, how severe. Please describe which side effects patients might be willing to accept or tolerate and which would be difficult to accept or tolerate)
- where the treatment has to be used (for example, in hospital rather than at home)
- impact on others (for example, family, friends and employers)
- financial impact on the patient and/or their family (for example, the cost of travel to hospital or paying a carer)
- any other issues not listed above

Please list any concerns patients or carers have about current NHS treatments in England.

Many patients and their loved ones have concerns about chemotherapy. Delaying or avoiding chemotherapy, or having a treatment option where chemotherapy is not an option, came through as a key theme of our survey in support of this submission (6).

Please list any concerns patients or carers have about the treatment being appraised.

The majority of respondents to our survey in support of this submission did not have any concerns about enzalutamide (72%). 25% stated they were 'unsure' and 3% did have concerns, which included the following (6):

"My concern was the risk of fits but this has not happened to me or any of the patients where I am being treated" – man diagnosed with prostate cancer.

If you know of any differences in opinion between patients or carers about the disadvantages of the treatment being appraised, please tell us about them.

One survey respondent (a man diagnosed with prostate cancer) stated that *"nobody should be given drugs for the short term unless they can say that it will be a cure, as all the money could be used to find a cure"* (6).

6. Patient population

Are there any groups of patients who might benefit more from the treatment than others? If so, please describe them and explain why.

Enzalutamide is an important treatment option for those men who are unable to receive, or who do not wish to receive, chemotherapy.

It is particularly beneficial for men who wish to delay treatment with chemotherapy, as enzalutamide can delay chemotherapy for an average of 17.2 months (7).

Enzalutamide is an important treatment option for those men who have previously attempted treatment with abiraterone, but have been unable to continue treatment due to dose-limiting toxicity.

Enzalutamide is not available on the Cancer Drugs Fund for men who have previously been treated with abiraterone, unless treatment with abiraterone had to be stopped within three months of starting, solely as a consequence of dose-limiting toxicity and in the clear absence of disease progression (13). We would challenge this decision if replicated by NICE. Although we acknowledge that there is not currently a huge volume of evidence to prove the efficacy of sequential use, the default position should not be to deny access.

Are there any groups of patients who might benefit less from the treatment than others? If so, please describe them and explain why.

Those who are unable to tolerate enzalutamide will not be able to benefit from it. On the Cancer Drugs Fund, these patients are allowed to switch treatment with enzalutamide to abiraterone within three months of starting, solely as a consequence of dose-limiting toxicity and in the clear absence of disease progression. This arrangement should remain in place for these patients.

7. Research evidence on patient or carer views of the treatment

Is your organisation familiar with the published research literature for the treatment?

☒ Yes ☐ No

Please comment on whether patients' experience of using the treatment as part of their routine NHS care reflects the experiences of patients in the clinical trials.

In the PREVAIL study, median time until QoL deterioration, as measured on the Functional Assessment of Cancer Therapy–Prostate (FACT-P) scale, was 11.3 months in the enzalutamide group and 5.6 months in the placebo group (7). QoL benefits were expressed in a response to our survey:

"I have a friend receiving it [enzalutamide] and it's amazing the change for the better he is" – man diagnosed with prostate cancer (6).

The PREVAIL study found a prostate-specific antigen (PSA) rate of decline of at least 50% in participants receiving enzalutamide (78% vs 3% in the placebo arm) (7). This is reflected in a man's experience of enzalutamide as part of his routine NHS care:

"I have been given Xtandi before chemo and after 1 month my PSA has significantly reduced and therefore believe it will defer the timing of my need for chemo" – man diagnosed with prostate cancer (6).

Adverse events recorded in the PREVAIL study, and experienced at a higher rate by those taking enzalutamide, included fatigue, back pain, constipation, arthralgia, hot flushes, hypertension and falls (7). Our survey asked men whether they regretted treatment decisions owing to side effects experienced. 96% of men who said they experienced fatigue did not regret their treatment choice; 91% who had experienced pain did not regret their treatment choice; and 97% did not regret treatment that resulted in hot flushes. Although we did not ask directly about constipation, we did ask about any experience of bowel incontinence as a side effect of treatment. Constipation is a leading cause of bowel incontinence. 91% of men who said they experienced bowel

incontinence said they did not regret their treatment choice (6). Our survey did not ask if men experienced hypertension or falls as a side effect of their treatment for prostate cancer.

Do you think the clinical trials have captured outcomes that are important to patients? Are you aware of any limitations in how the treatment has been assessed in clinical trials?

Respondents to our opinion survey placed the highest value on overall survival (OS) outcomes and QoL benefits (98% and 99%, respectively) (5). OS and QoL were also strong recurring themes in the responses to our survey in support of this submission (6). The PREVAIL study captured OS data, and QoL data using the FACT-P scale. Use of the FACT-P scale has been supported as a 'meaningful component of QoL evaluation in men undergoing therapy for prostate cancer' (14). We do not believe there are limitations in how enzalutamide has been assessed for both OS and QoL in the PREVAIL trial.

The PREVAIL trial also captured time to initiation of cytotoxic chemotherapy, which is an important outcome measure to the chemotherapy naïve prostate cancer patient population. Respondents to our survey in support of this submission highlighted the benefits of delaying chemotherapy, as well as the importance of having a treatment option where chemotherapy is unsuitable (6).

If the treatment being appraised is already available in the NHS, are there any side effects that were not apparent in the clinical trials but have emerged during routine NHS care?

We have not been made aware of any additional side effects that were not already apparent in the PREVAIL trial. These data should be collected as part of Cancer Drugs Fund prescribing data and fed into this appraisal.

Are you aware of any relevant research on patient or carer views of the condition or existing treatments (for example, qualitative studies, surveys and polls)?

☒ Yes ☐ No

If yes, please provide references to the relevant studies.

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- Prostate Cancer UK. Men's views on quality care in prostate cancer: What does good quality care mean for men with prostate cancer? Total sample size was 610 UK men. Fieldwork was undertaken between October 2011 and January 2012 [Internet]. 2012. Available from: http://prostatecanceruk.org/media/1559431/prostate_cancer_uk_quality_care_survey_report_june_2012.pdf
- Prostate Cancer UK. Hampered by Hormones [Internet]. [cited 2013 Jun 21]. Available from: http://prostatecanceruk.org/media/49198/htcampaignreport.pdf
- Prostate Cancer UK. 'A survey of the public's views on Xtandi® (enzalutamide) becoming a treatment option for men with advanced prostate cancer, who have not previously received chemotherapy'. Total sample size was 267 UK adults which included men with prostate cancer and friends/family of men with prostate cancer. Fieldwork was undertaken between 7th January and 1st February 2015. The survey was carried out online. 2015.
- Prostate Cancer UK. Value-based pricing: Getting it right for people with cancer [Internet]. 2012 [cited 2013 May 10]. Available from: http://prostatecanceruk.org/media/1633387/1513_value-based_pricing_report_for_print.pdf
- Ream E, Quennell A, Fincham L, Faithfull S, Khoo V, Wilson-Barnett J, et al. Supportive care needs of men living with prostate cancer in England: a survey. Br J Cancer. 2008 Jun 17;98(12):1903–9.

8. Equality

NICE is committed to promoting equality of opportunity, eliminating unlawful discrimination and fostering good relations between people with particular protected characteristics and others. Protected characteristics are: age; being

or becoming a transsexual person; being married or in a civil partnership; being pregnant or having a child; disability; race including colour, nationality, ethnic or national origin; religion, belief or lack of religion/belief; sex; sexual orientation.

Please let us know if you think that recommendations from this appraisal could have an adverse impact on any particular groups of people, such as:

- excluding from full consideration any people protected by the equality legislation who fall within the patient population for which the treatment is/will be licensed;
- having 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 treatment;
- any adverse impact on people with a particular disability or disabilities.

Please let us know if you think that there are any potential equality issues that should be considered in this appraisal.

None.

Are there groups of patients who would have difficulties using the treatment or currently available treatments? Please tell us what evidence you think would help the Committee to identify and consider such impacts.

Enzalutamide is an important treatment option for men with chemotherapy naïve metastatic hormone-relapsed prostate cancer and visceral disease. These patients are not served by current therapies: abiraterone is not available to chemotherapy naïve prostate cancer patients with visceral disease (12) because the COU-AA-302 study of abiraterone excluded these patients (8); radium-223 is limited to patients who have no known visceral metastases (15); and cabazitaxel is going to be removed from the Cancer Drugs Fund on 12 March 2015. As the PREVAIL study of enzalutamide included patients with visceral disease and demonstrated clinical benefits in this group (7), enzalutamide is available for these patients via the Cancer Drugs Fund (12).

9. Other issues

Do you consider the treatment to be innovative?

☒ Yes ☐ No

If yes, please explain what makes it significantly different from other treatments for the condition.

Enzalutamide has a different mode of action to abiraterone. Enzalutamide is an androgen receptor antagonist, whereas abiraterone stops androgen production.

Enzalutamide provides a significantly longer time to initiation of cytotoxic chemotherapy than comparator abiraterone (17.2 months (7) vs 9.7 months (8), respectively).

Enzalutamide is an important treatment option for men with chemotherapy naïve metastatic hormone-relapsed prostate cancer and visceral disease (12): abiraterone is not available to chemotherapy naïve prostate cancer patients with visceral disease (12); radium-223 is limited to patients who have no known visceral metastases (15); and cabazitaxel is going to be removed from the Cancer Drugs Fund on 12 March 2015 (12).

Are there any other issues that you would like the Appraisal Committee to consider?

Real-world outcomes data from prescribing via the Cancer Drugs Fund should be considered as part of this appraisal.

10. Key messages

In no more than 5 bullet points, please summarise the key messages of your submission.

- Delaying chemotherapy is a benefit that is valued by men with prostate cancer and their friends and family members (6). Enzalutamide has been shown to provide an average of 17.2 months time to initiation of cytotoxic chemotherapy, which is 7.5 months more than is offered by comparator abiraterone (7,8).
- For some men, chemotherapy is not an option. At least 20 to 40% of patients with metastatic prostate cancer never receive chemotherapy (9–11). Enzalutamide addresses an important unmet need in the chemotherapy naïve prostate cancer population that is not routinely served by current therapies.

- A high majority of people affected by cancer place value on treatment that can extend life (5,6). Enzalutamide has been shown to extend life by an average of 2.2 months compared with placebo.
- A high majority of people affected by cancer place value on treatment that is not detrimental to the patient's QoL (5,6). The PREVAIL study found a median of 11.3 months time until decline in the FACT-P global score, which is 5.7 months more than was seen in the placebo arm (7).
- Enzalutamide is an important treatment option for men with chemotherapy naïve metastatic hormone-relapsed prostate cancer and visceral disease (12): abiraterone is not available to chemotherapy naïve prostate cancer patients with visceral disease (12); radium-223 is limited to patients who have no known visceral metastases (15); and cabazitaxel is going to be removed from the Cancer Drugs Fund (12).

References

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Appendix 1

What would extra time towards the end of life mean to you?

"I am not an 'old' man at 58 and would appreciate every extra day" – man diagnosed with prostate cancer.

"It is quite hard to imagine how much even two extra months can mean until you face being given or denied that time" – man diagnosed with prostate cancer.

"Two months longer on your life is priceless; family moments are precious" – family member of a man who has died from prostate cancer.

"Any chance of extra time is precious with a loved one living with cancer" – friend/family member of man who has died from prostate cancer.

"More time to spend with my 46 year old husband" – partner of a man diagnosed with prostate cancer.

"Time for making more memories … More time together before saying goodbye" – partner of a man diagnosed with prostate cancer.

"More time with my family" – man concerned about prostate cancer.

"Although I am 63 I don't feel old and want many more years to enjoy with my family" – man diagnosed with prostate cancer.

"Time with family and be able to put my affairs in order" – man concerned about prostate cancer.

"The chance to bring closure to some aspects of my life, prepare myself and family for my death, 'put my house in order'" – man diagnosed with prostate cancer.

"To reconcile and adjust myself to dying, a chance to make a peaceful ending with my friends and loved ones" – man diagnosed with prostate cancer.

"Continue to work and be a valuable member of society" – man diagnosed with prostate cancer.

"I would probably be able to carry on working, as I still do on ADT, and therefore contributing to the support of my family and (in the form of work and taxes) to society and the state" – man diagnosed with prostate cancer.

"A chance to continue my contribution to life and society for longer" – man diagnosed with prostate cancer.

"If men who are still working can take Xtandi and still continue to work that must be beneficial to all parties" – man diagnosed with prostate cancer.

"The opportunity to fulfil some life ambitions after 47 years of constant work, many without holidays" – man concerned about prostate cancer.

"I could fit in as many of those things I have always wanted to do but haven't because of saving for my old age which I no longer need to do" – man diagnosed with prostate cancer.

"It would mean everything – as long as it was quality *time"* – friend/family member of man who has died from prostate cancer.

"It would mean more quality time with loved ones rather than in a nursing home because he was so poorly" – friend/family member of man who has died from prostate cancer.

"Any quality extra time would have been good" – friend/family member of man who has died from prostate cancer.

"It would mean everything as long as he is not suffering" – partner of a man diagnosed with prostate cancer.

"It would mean everything if their QoL could be improved – even if only for a short time" – partner of a man diagnosed with prostate cancer.

"Anything to improve their quality of life" – partner of a man diagnosed with prostate cancer.

"Everything, if it was good quality for him" – partner of a man diagnosed with prostate cancer.

"Would want my husband to be with me as long as possible but not to be suffering" – partner of a man diagnosed with prostate cancer.

"An enormous gift but not at the expense of dreadful side effects" – partner of a man diagnosed with prostate cancer.

"Depends on quality of life and side effects as well as how much extension of time" – man concerned about prostate cancer.

"Be amazing to have extra time to live but not in pain and suffering" – man diagnosed with prostate cancer.

"Would mean a great deal, depending on quality of life" – man diagnosed with prostate cancer.

"Fantastic if coupled with quality of life provided by enzalutamide" – man diagnosed with prostate cancer.

"Life is precious and if treatment can extend it while retaining a moderate quality of life this will be important to me and my dependents" – man diagnosed with prostate cancer.

"Extra time is surely the aim of all treatments for advanced prostate cancer but is only of value if the extra time is quality time i.e. not two additional months of pain in a hospice" – man diagnosed with prostate cancer.

Appendix 2

Should enzalutamide be available to men with advanced prostate cancer, who have not previously received chemotherapy?

"I think if there is a drug or treatment that could make my dad and other men live longer then it should be available for them before they have to go through the mental/physical strains and stresses of chemotherapy. Please!" – family member of a man who has died from prostate cancer.

"My personal experience includes radiotherapy, hormone based treatments and chemotherapy; I am very clear that I would always prefer, if possible, to have radiotherapy and hormone treatment earlier in the cycle than chemotherapy, because in terms of likelihood and severity of side effects chemotherapy is far more intrusive into quality of life while under treatment. Also the method of administration is significant – a full day at clinic having chemotherapy infusion, generally followed by a period of some days (for me usually 2-3 days) of extreme tiredness and incapacity, eats quite a lot of time out of the survival days gained by each treatment. Administration of hormone treatment as tablets taken daily is free of most of that cycle of illness that accompanies chemotherapy – and this is of greatest benefit in the earlier stages of disease progress when general fitness and health levels are higher" – man diagnosed with prostate cancer.

"We have a twelve year old son, and last year for the first time in ages we went on holiday as a family, because my husband was fit enough to drive due to the drugs he is on. However, it looks as though these drugs have now stopped working. He is frightened of chemotherapy because of the side effects, and the fact that he will probably have to give up work if he does have chemo. We have lived relatively normal lives up to now. If he were able to take tablets we could still have such a life. I am dreading him having chemo myself because I shall have to give up work as well – I don't get paid if I don't work" – partner of a man diagnosed with prostate cancer.

Appendix 3

Do you think enzalutamide will have benefits for men with advanced prostate cancer, who have not previously received chemotherapy?

"It is deemed that chemo would kill my husband in view of heart condition now … so the chance to have this new drug without chemo would be a great opportunity for him" – partner of a man diagnosed with prostate cancer.

"Not everyone can tolerate docetaxel. This would give them an alternative" – partner of a man diagnosed with prostate cancer.

"Chemo can make people weaker so trying Xtandi first may be more beneficial" – partner of a man diagnosed with prostate cancer.

"Chemo is such an aggressive treatment for an older man to go through, it can really affect quality of life so drastically so these earlier drugs really make all the difference" – friend/family member of a man diagnosed with prostate cancer.

"Other conditions deemed chemo to be too risky in my husband's case, but hopefully enzalutamide may help him once HT is no longer efficient" – partner of a man diagnosed with prostate cancer.

"It should be the oncologist/specialist who has the option and knows the patient and the drug, who decides when it is prescribed either before or *after chemo"* – partner of a man diagnosed with prostate cancer.

"Anything that helps fight this terrible condition and provides quality of life. Chemo isn't great for anyone, but for an older person it was a complete nightmare" – friend/family member of a man who has died from prostate cancer.

"If it can prolong the time before chemo is needed this could give him a better quality of life for longer" – friend/family member of a man diagnosed with prostate cancer.

"Chemotherapy makes people ill and most don't recover completely from having had this" – partner of a man diagnosed with prostate cancer.

"This [enzalutamide] is an option which would be suitable for many men. The impact of chemo is minimal at an advanced stage and the side effects significant. This option is potentially less intrusive in terms of quality of life which is a very important factor with advanced prostate cancer" – friend/family member of a man who has died from prostate cancer.

"Chemotherapy is a traumatic experience with serious side effects" – man diagnosed with prostate cancer.

"I see chemotherapy as last resort, after all other options used" – man diagnosed with prostate cancer.

"I think it [enzalutamide] would have been a better alternative, my husband had chemotherapy first, the enzalutamide brought his PSA down markedly, this drug should be offered first, with little or no side effects as opposed to the side effects of chemotherapy" – partner of a man who has died from prostate cancer.

Appendix 4

"I look and feel well, so the longer I can 'hang on', the better the chance of new treatments coming along to give me even more time – I'm not ready to die just yet" – man diagnosed with prostate cancer.

"There is never enough time however the availability of this drug would have provided us with hope and choice, realistic to the stage of cancer my dad suffered. An extension of time would have allowed us to talk more, hug more and support my dad more rather than the only other gruelling option of chemo" – family member of man who has died from prostate cancer.

"Every man should have the right to choose whether they have this treatment. It is a human right. Why manufacture the drug and then decide it cannot be available to all. If there is anyway that people can access a life saving treatment then who has the right to deny them. I had my prostate removed last year and I am extremely grateful for my life saving operation. I chose this over radiotherapy and that was my own personal choice. People need choices and I feel very strongly about this" – man diagnosed with prostate cancer.

"Doctors and patients need choice. Xtandi would add to that choice" – man diagnosed with prostate cancer.