



Healthcare  
Improvement  
Scotland

SMC  
Advice on new  
medicines

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# Patient Group Submission Form

The Scottish Medicines Consortium (SMC) is committed to working in partnership with patient groups to capture patient and carer experiences, and use them to inform decision-making.

## Before you make a submission

You are required to complete a patient group partner registration form before you make a submission. The registration form requests general information about your organisation. It only needs to be completed once (and annually updated) and should save you time with any further submissions to SMC. If you have not already completed a registration form, please do this before you make your submission.

You will find it helpful to read our *Guide for Patient Group Partners*, which gives details about the type of information you need to capture in the submission form. **Please read this before you make your submission and use it to help you complete each question.**

You can find the registration form and *Guide for Patient Group Partners* in the [Public involvement](#) and [Making a submission](#) sections of our website.

## Contact us

If you have any more questions after reading the guide, the SMC Public Involvement Team can support you throughout the submission process. You can email us at:

[hcis.SMCPublicInvolvement@nhs.net](mailto:hcis.SMCPublicInvolvement@nhs.net) or phone: **0141 414 2403**.

Please do not hesitate to get in touch, as we are here to help you.

Name of medicine:

Enzalutamide (Xtandi)

Indication: (what the medicine is used for)

Prostate Cancer

Submission date:

27th June 2019

Name of organisation making submission:

Edinburgh & Lothian Prostate Cancer Support Group

Who is the main contact for submissions to SMC?

Name:

Rob Lester

Position held in organisation:

Committee representative

Email address:

Phone number:

Postal address:

## Summary of key points

Please summarise the key points of your submission which you would like to emphasise to SMC Committee – bullet points may be helpful.

(See P11 of *A Guide for Patient Group Partners*)

300 words maximum

1. Prostate cancer is a common cancer with a high death rate
2. The treatment for advanced prostate cancer is improving
3. Enzalutamide is a proven successful treatment for advanced prostate cancer and is known to help delay the onset of spread in men with High Risk Prostate Cancer
4. We feel that it is now time for men with High Risk Prostate Cancer to get Enzalutamide (Xtandi) as first line treatment if the cancer is known to be very active

Please provide details of any individuals who have had a significant role in preparing your submission and who have an interest to declare.

(See P11 of *A Guide for Patient Group Partners*)

300 words maximum

Rob Lester. No significant interest to declare.

Please tell us how you gathered information about the experiences of patients and carers to help inform your submission.

(See P11 of *A Guide for Patient Group Partners*)

300 words maximum

We contacted our members and asked if any of them have experience of treatment with Enzalutamide or know what it is like to have a rapid rise in PSA levels detected within a period of 10 months.

Also our support group has regular meetings, where we discuss new treatments for prostate cancer and share our experiences of past and present treatments.

## 1. How does this condition affect the day-to-day lives of people living with it?

(See P11 of *A Guide for Patient Group Partners*)

500 words maximum

Advanced prostate cancer can cause significant tiredness, bone pain, distressing urinary symptoms, anxiety and low mood disorder. Most men become restricted in their activities as the disease progresses and require higher levels of pain relief with more intensive cancer treatments. About 30% of our members have advanced prostate cancer and there is great hope that recent treatment improvements will lead to longer and better quality of life for the men with cancer, as well as more precious time with their carers and families.

## 2. How well do medicines which are currently available in NHS Scotland help patients manage this condition? (See P12 of *A Guide for Patient Group Partners*)

500 words maximum

Current treatments such as chemotherapy have made a big difference to the quality and extent of people's lives. Also Enzalutamide, Abiraterone and Radium 223 have been successful in helping men who have castration resistant prostate cancer.

These are the words of a man who has had several treatments for advanced prostate cancer and has managed to live a full and enjoyable life despite the side effects of pain, deafness and tiredness caused by some of these treatments.

'I started treatment with Enzalutamide in January 2014 and finished with it in September 2015. I had Docetaxel and Zometa previously as part of the Trapeze Trial and, after the Docetaxel bit was finished, carried on with Zometa until my tests became a bit more adverse. Enzalutamide was next as my consultant saw it as a better choice than a different chemotherapy drug. I remember it was very successful for me and with low (if any) side effects. Eventually it stopped being effective, my tests going in the wrong direction and I think next was Cabazitaxel, with reasonable benefits, but after the sixth cycle very bad side effects. Then after a gap it was on to Radium 223. I did benefit from Enzalutamide and support its earlier use.'

3. Have you been able to consult with patients who have used this medicine?

(See P12 of *A Guide for Patient Group Partners*)

Yes  No

4. Would this medicine be expected to improve the patient's quality of life and experience of care, and if so, how?

(See P12 of *A Guide for Patient Group Partners*)

500 words maximum

Yes the quality of life and experience of care would improve as there are few side effects and the medicine is easy to take in tablet form. There is also a positive benefit in knowing that early intervention is possible and that the inevitable onset of metastatic disease could be delayed.

This is what a man, who is receiving chemotherapy and has benefitted from early treatment with hormone injections, wrote and might have had his cancer spread delayed if Enzalutamide had been given earlier.

'I was diagnosed with advanced Prostate in October 2018. I went from Borderline in June 2018 to 9.1 in a month. I don't know what it was prior to treatment. However treatment started immediately with Hormone Therapy which has lowered the PSA down to 0.1 which is pleasing everyone including myself. I have had 6 sessions of Chemo and am starting 4 weeks of Radiotherapy this week. I realise the benefit of early treatment for High Risk prostate cancer and support the use of Enzalutamide for men who, like me, have a sudden rise in their PSA results and have not yet been diagnosed with advanced prostate cancer'.

5. What kind of impact would treating a patient with this medicine have on the patient's family or carers? (See P13 of *A Guide for Patient Group Partners*)

500 words maximum

The family and carers will be able to enjoy better quality time with the men who have advanced prostate cancer and also have more months or years to spend together.

These words are from a man who thought his cancer had been cured and is now living with the reality that his PSA is rising rapidly and little can be done to prevent the cancer becoming metastatic. This is devastating news for his family who wish that a treatment, like Enzalutamide, was there to try and contain the spread.

'I was recently re-diagnosed with locally advanced prostate cancer and my doubling period has been calculated at approximately 4½ months. Had this option of Enzalutamide been available at the time of re-diagnosis, I would certainly have given this treatment option consideration'.

6. Are there any disadvantages of the new medicine compared to current standard treatments? (See P13 of *A Guide for Patient Group Partners*)

500 words maximum

Although side effects are few they can be serious and this is the experience of a man who had to stop Enzalutamide

'My PSA started to rise from 5.8 in July 2017, to 8.6 in October 2017, then 11.9 in January 2018, which was basically doubling in 6 months. It was then in January 2018 I commenced taking Enzalutamide.

Unfortunately, the unpleasant side effects (joint Pain) I was experiencing with Enzalutamide combined with my PSA going up to 14.1 in May 2018 then doubling to 28 in June 2018 it was obviously not working for me!

Chemotherapy was the next step.

Although Enzalutamide did not work for me, I realise that others might benefit on the understanding that there is careful monitoring for potential side effects.'

7. Is there any additional information you think may be useful for the SMC committee to consider? (Optional)

500 words maximum

The Edinburgh & Lothian Prostate Cancer Support Group supports the innovative new use of Enzalutamide in the treatment of High Risk Castration Resistant prostate cancer and hopes that this drug will not be prohibitively expensive for use by the NHS in Scotland.

8. Do you consent for a summary of your submission to be included in the Detailed Advice Document for this medicine?

Yes

No

Thank you for completing this form.

Please email it to: [hcis.SMCPublicInvolvement@nhs.net](mailto:hcis.SMCPublicInvolvement@nhs.net)

If you are unable to email this form to us, please send by post to the address below:

Public Involvement Team  
Scottish Medicines Consortium  
Healthcare Improvement Scotland  
8<sup>th</sup> Floor  
Delta House  
50 West Nile Street  
G1 2NP

The Public Involvement Team is available to advise you on how to complete this form to ensure the patient and carer experience is fully captured, to help inform the SMC decision making process. If you have any questions about completing this form call us on: 0141 414 2403.