

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Single technology appraisal (STA)

Fulvestrant for locally advanced or metastatic breast cancer

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: **Marie M Hecht**

Name of your organisation: **None - I am a Patient on Fulvestrant**

Are you (tick all that apply):

Yes I am 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)
- 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.

Having already been on Arimidex, Tamoxifen and Aromasin, I am hoping that Fulvestrant will continue to control my cancer for many years to come and prevent the progression of the disease for as long as possible. So far it has controlled my cancer since January 2009 – much longer than any of the other treatments.

(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.

- I am hoping that my reviews will continue to be at 6 monthly intervals (instead of 3), as this enables me to plan further ahead than has so far been possible since being diagnosed with SBC in 2008.

- The longer the Fulvestrant works the more able I feel to 'relax' and feel 'confident' that life can go on as normal for the time being. The pressure of the 3 monthly check has been lifted – at least for the time being! This allows me to put the knowledge that I am incurable into my 'lidded box' in my mind, and put the lid on firmly until it is time for my next review.

- The size of my metastasis in the lung seems to have shrunk slightly since being prescribed Fulvestrant.

- I prefer the injection to taking tablets as I feel this is better for my particular body – for example, pain relief has always been most successful when given as an injection – tablets rarely work well.

What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition? (continued)

2. Disadvantages

Please list any problems with or concerns you have about the technology. Disadvantages might include:

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

- I often have severe bruising and swelling at the site of the injection, but feel that this is a small price to pay for the control Fulvestrant provides over my cancer.

- I have very strong flushes at times, but again I can tolerate this side effect.

- It would seem that my skin has become more sensitive since I started Fulvestrant – redness and itching, with weals appearing where I have been touched/scratched.

This is worse when I am hot e.g. doing Scottish Dancing! This is helped by taking anti-histamine tablets on a daily basis.

- Vaginal dryness.

- Adverse effect on bone density.

3. Are there differences in opinion between patients about the usefulness or otherwise of this technology? If so, please describe them.

I do not know any fellow secondary patients on Fulvestrant so cannot make any comment.

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?

Triple negative patients cannot benefit from Fulvestrant whereas oestrogen positive patients, like myself, are able to do so.

Comparing the technology with alternative available treatments or technologies

NICE is interested in your views on how the technology compares with with existing treatments for this condition in the UK.

(i) Please list any current standard practice (alternatives if any) used in the UK.

- I am happy to think that I am being spared Chemotherapy for the time being.

- The other treatment (Aromasin) I have been given since I was diagnosed with secondary worked for less than 6 months.

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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 in 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.)

- Fulvestrant has worked for longer than any of the other endocrine treatment I have been given and has also resulted in a slight shrinking of the tumour in the lung.
- It doesn't involve all the side effects that chemotherapy entails.

(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).

In my mind, the advantages of the benefits of Fulvestrant outweigh any disadvantages.

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.

As a patient I do not have the experience/knowledge to answer this question.

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

There is no mention of the skin problem that I experience in the list of possible side effects.

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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.

Unable to answer.

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?

- It would enable other patients to have the chance to benefit from the possible stabilisation of their cancer if Fulvestrant was approved for general use.
- It could provide others with the chance of extra years of a good quality of life - up until it stops working and the disease progresses.

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

The opposite of the previous answer – it would deny patients the possible chance to do the things they still want to do – such as be with their families, continue to work, see children grow up and generally enjoy life with their friends and loved ones.

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

Anyone with a phobia of injections or unable to cope with the side effects may have difficulties with Fulvestrant.

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Other Issues

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