Appendix G – Patient/carer organisation statement template

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Single Technology Appraisal (STA)

Pertuzumab in combination with trastuzumab and docetaxel for the treatment of HER2 positive metastatic or locally recurrent unresectable 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: Tara Beaumont

Name of your organisation: Breast Cancer Care

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?
- X 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) Clinical Nurse Specialist- metastatic breast cancer
- 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.

The data from the CLEOPATRA study demonstrated progression free survival (PFS) was significantly better in the pertuzumab arm of the study, with an approximate increase of 6 months PFS. Data also showed possible increase in overall survival, but data was not mature at time of article publication (Baselga 2012).

Metastatic breast cancer is a life limiting disease; average survival data suggests one-year survival rates of 55%, two-years 35% and five-year survival rates of just 20% (Glare and Christakis 2008). Patients frequently experience ongoing symptoms due to the disease, control of the disease progression is therefore important to maintaining a good quality of life for as long as possible. For patients with metastatic breast cancer the importance of quality of life must not be underestimated. Patients frequently talk with us at Breast Cancer Care, telling us they want access to treatments that will give them improved quality of life to spend more quality time with their friends and families.

(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

Benefits to patients may include control of physical symptoms; maintain a good quality of life, including time spent with family and friends. Early data suggest a possible overall survival benefit of even a few months or weeks is extremely

important to this client group, where life expectancy is significantly reduced due to the disease progression.

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)

Side-effects experienced by patients in the study were considered tolerable. Patients often tell us they are willing to experience significant side-effects to gain control of the disease and hope for a potential survival benefit, even of a few weeks or months.

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

None known

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?
This technology is only suitable for patients with HER2 positive breast cancer

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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.

IV Herceptin in combination with chemotherapy, usually a Taxane

(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)

The data from the CLEOPATRA study demonstrated progression free survival (PFS) was significantly better in the pertuzumab arm of the study, with an approximate increase of 6 months PFS. Data also showed possible increase in overall survival, but data is not mature at time of article publication (Baselga 2012).

This technology is a new drug, the advantage being it is given at the same time as current standard therapy, therefore additional visits to the hospital are not required by the patient, nor additional venous access.

The side-effects experienced in the pertuzumab arm of the study were within tolerable levels. Patients in contact with Breast Cancer Care, who have been receiving pertuzumab, have not reported unacceptable side-effects.

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(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).

None known

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.

Patients in contact with Breast Cancer Care, who have received pertuzumab, have reported tolerable side-effects.

Are there any adverse effects that were not apparent in the clinical trials but have come to light since, during routine NHS care?
None known

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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.

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?

The data from the CLEOPATRA study demonstrated progression free survival (PFS) was significantly better in the pertuzumab arm of the study, with an approximate increase of 6 months PFS. Data also showed possible increase in overall survival, but data is not mature at time of article publication (Baselga 2012).

Patients frequently talk with us at Breast Cancer Care, telling us they want access to treatments that will give them improved quality of life to spend more quality time with their friends and families.

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

To not have access to this new drug via the NHS would potentially mean patients are denied the opportunity to gain control of their disease for a significant amount of time,

and potentially be denied the possibility of extending their life, even by a few months, which patients report to us as being extremely important.

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

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.

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

References cited;
Baselga J (2012) Pertuzumab plus Trastuzumab plus Docetaxel for Metastatic breast cancer *The New England Journal of Medicine*

Glare P Christakis NA (Eds) (2008) Prognosis in Advanced Cancer Oxford Oxford University Press