Appendix G – patient/carer organisation statement template

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal (STA)

Trastuzumab emtansine for treating HER2-positive, locally advanced or metastatic breast cancer after treatment with trastuzumab and a taxane

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: [redacted]

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?
- ☒ 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.

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 disease progression is therefore crucial 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 contact us at Breast Cancer Care, telling us they want access to treatments that will give them improved length and quality of life.

Results from the TH3RESA phase III study showed an increase in PFS (progression free survival) compared to the trial arm of around 3 months (median 6.2 months vs. 3.3 months, respectively). This increase in PFS is significant for patients living with metastatic breast cancer.
Study data showed a reduction in toxicity experienced by patients on the T-DM1 arm of the study. Patients receiving the drug have reported anecdotally to Breast Cancer Care the importance of reduced toxicity and its impact on quality of life..

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

www.medscape.com/viewarticle/811845 last accessed 30.10.13

ECC 2013 press release: Anti- cancer drug T-DM1 Benefits women with advanced breast cancer who have failed previous treatments: Results from TH3RESA trail www.esmo.org/ European- Cancer- Congress 2013 last accessed 18.11.13

(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; maintaining a good quality of life, including time spent with family and friends.

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)

This treatment regime requires an outpatient appointment, however many patients are willing to attend the hospital for treatment and welcome the opportunity to be in contact with their specialist team.

Travel costs to hospital appointment can be a concern for some patients including the cost of car parking.

Many patients will need a family member or friend to accompany them on hospital visits due to the nature of the illness.

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

None known

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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

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.

This technology based on the TH3RESA study is considered an additional treatment option for patients with HER2 positive metastatic breast cancer

(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)

(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).

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.

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?

Patients with metastatic breast cancer tell us at Breast Cancer Care that improved PFS increases their quality of life which is vitally important for this group of patients who are facing a life limiting illness. A good quality of life which enable them to spend important time with family and friends cannot be underestimated.

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

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

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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.

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