Appendix G – patient/carer organisation statement template

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal (STA)

Afatinib for treating epidermal growth factor receptor mutation positive locally advanced or metastatic non-small cell lung 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 advocatescanprovideauniqueperspectiveon the technology,whichisnottypicallyavailablefromthepublishedliterature.

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: ROY CASTLE LUNG CANCER FOUNDATION

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). YES [redacted].
- 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.

Roy Castle Lung Cancer Foundation does not have any data on this technology, beyond that in the public domain. Our comments are based on knowledge of the disease and on anecdotal comments from patients who have received the therapy.

In this appraisal, Afatanib is being assessed in EGFR mutation positive patients. These are a small segmented number of nsclc patients. At present these patients should receive Gefitinib or Erlotinib in the first line. The use of Afatinib, dependent on clinical data and licence, will be either in first llne (should data show clinical benefit over Erlotinib and Gefitinib) and / or in second line, after failure of Gefitinib or Erlotinib .

'EGFR mutation positive' lung cancer is found in a relatively small selected group of patients. It is clear that this group has different tumour biology, as compared with nsclc in general. Current targeted therapies in this group, though of clinical benefit do not provide a cure and as such, additional options in this often devastating disease are of immense importance.. .

Improving quality of life and extension of life is of real importance in this patient group.

(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

Extension of life, improvement in quality of life. Also, as compared with intravenous chemotherapy, ability to take an oral therapy, ensure less time in hospital and more at home, work etc.....

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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 effect profile of diarrhoea etc.. Side effects should be minimised by good patient information, prophylactic management, dose reduction etc...
An oral therapy, therefore, reduced hospital costs etc...

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

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?

Not aware of any – EGFT mutation positive population.

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.

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See appraisal Scope

(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)

Ease of use, where compared with intravenous chemotherapy. Reduce costs 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 examplein hospital rather than at home)
- sideeffects (for examplenature or number of problems, how often, for how long, how severe).

Different side effect profile from Gefitinib and Erlotinib

Research evidence on patient or carer views of the technology

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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?

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?

Only recent understanding of this segmented lung cancer population. This therapy would provide an additional therapy option, tailored to this patient group.

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

Patients would be denied access to it. A high proportion of lung cancer patients come from more socially disadvantaged groups. This patient group has little or no private insurance nor any likelihood of attaining it because of their age, social deprivation characteristics and the fact that many have other co-morbidities. Thus the vast majority would not be in a position to afford to buy Afatanib on a private basis

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.

As part of the assessment, the Appraisal Committee should take account of the innovative nature of this new therapy. And, dependent on licenced indication, whether Afatinib meets 'End of Life' criteria.